

Utilizing a Phenomenological Approach to Examine the Experience of Sexuality for Women Concerned about Urinary Incontinence following Spinal Cord Injury

Jackie Cramp, B.Kin

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Supervisor: David Ditor, PhD

Faculty of Applied Health Sciences
Brock University
St. Catharines, ON.

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I dedicate this paper to my supervisor, Dr. David Ditor, who I would like to thank for helping me become the student and researcher I am today, as well as to Dr. Frederique Courtois for introducing me to the topic of sexuality after spinal cord injury, and Dr. Maureen Connolly who has guided me through every step of my first qualitative research study.

I also dedicate this paper to my parents, Tim and Janet, and to Michael, Bill and Jennie Massie.

Thank you for all of your support and encouragement, I appreciate it more than you know.

Abstract

Urinary incontinence (UI) affects a woman's sexuality after spinal cord injury (SCI) physically and psychologically. Seven phenomenological interviews combining interview guide and standardized open-ended approaches were conducted to examine the experience of sexuality for women concerned about UI following SCI.

Sexuality concerns included being injured, being sexually unsatisfied, and difficulties with relationships and body image. Urinary incontinence concerns included bladder infections, embarrassment, and side effects of UI medications. Effects of UI on sexuality were anxieties regarding incontinence during sexual activities, disclosure and rejection, a comparison to the way things were before, a connection between sexual sensations and UI, and frustration with the lack of resources and well-informed health-care providers.

Addressing sexual function and UI which are among the top concerns for this population has the opportunity to improve their quality of life. Resources providing knowledge and support should be made available to women with SCI, their partners and their Doctors.

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Chapter One- Introduction

Individuals who have sustained a spinal cord injury (SCI) will experience impairment of the communication between their brain and their body. This impairment affects numerous body functions including mobility, sensation, regulation of body temperature and bladder and bowel function to name a few. The extent of impairment, and which body areas and functions are affected will depend on the level and severity of the SCI. A person with SCI would be classified as paraplegic if the lesion was at the thoracic level or lower. This type of injury typically results in impairments to the legs and pelvic organs, and depending on the exact level, some amount of the trunk as well. Having a lesion in the cervical region of the spinal cord would be classified as tetraplegia, and would cause impairments to the arms, trunk, legs and pelvic organs. A SCI is also classified as being either incomplete when some motor and sensory function remains intact, or complete in the event that there is no preserved sensory or motor function at some level below the level of the injury (Saladin, 2004).

Impairment to any of the body functions listed above would affect the experience of sexuality for an individual with SCI. Sexuality and sexual function research is somewhat limited due to its taboo nature, and this is the case even more so for individuals who have a chronic disability (Verschuren, Enzlin, Dijkstra, Geertzen, & Dekker, 2010). Women with SCI have been especially overlooked with regards to sexual function for a number of reasons, yet previous research has outlined women's continued interest in sexuality post-SCI (Reitz et al., 2004). The present investigation has again confirmed that sexual function is actually one of the primary concerns for women after SCI.

Bladder function is almost always affected by SCI because the nerves that control the urinary system are located at the base of the spinal cord between S2-S4, consequently they become interrupted or disconnected from the brain. Since issues with bladder function and urinary incontinence (UI) are incredibly common, and because bladder function is necessary for survival, there is a considerable amount of information regarding the topic. However, it takes a substantial amount of time to establish an effective urologic management program, and it requires a great deal of trial and error. Many individuals continue to experience issues with their bladder, and/or a concern about bladder issues that affects their daily lives. Urinary incontinence is a major concern for women with SCI (Hicken Putzke, & Richards 2001), and UI may also have an effect on sexuality and sexual function. To the knowledge of this author, this connection has not yet been explored and there is very little information available regarding sexuality and sexual function as it relates to UI.

Novel and exploratory research of this topic is well suited to qualitative methodology as the researcher would have the opportunity to delve into the unique and personal understandings of the experiences of women who have first-hand knowledge on the phenomenon. Phenomenological interviews have the potential to uncover the views and beliefs, as well as the concerns and priorities of this population regarding the experience of sexuality taking into account a concern for UI. This knowledge base could help inform the development of bladder management and sexual function strategies, as well as the preferred methods of knowledge translation to the target audience. Enhanced understanding of the meaning and importance of UI, sexual function, and the relationship between the two topics should be an essential concern for researchers, as well as

rehabilitation and health care providers to ensure that future therapies and treatments target the top consumer-identified issues and improve quality of life (QOL).

This study aims to answer the following research questions: *What is the experience of sexuality for women who are concerned about urinary incontinence following spinal cord injury? What impact does urinary incontinence have on sexual function and sexual satisfaction in women with spinal cord injury?* and *What are the main concerns regarding urinary incontinence and sexuality for women with spinal cord injury?*

Chapter Two- Review of the Literature

1.1 Background

For an individual with SCI, incontinence is one of the many negative consequences that may become a concern of everyday living (Reitz, Tobe, Knapp, & Schuech, 2004). For an adult, being incontinent is considered socially unacceptable and socially devastating (Do Ngoc Thanh, Audry, & Forin, 2009; Horton, Chancellor, & Labatia, 2003; Shuttleworth, 1970).

Sexual function is the number one therapeutic priority for many individuals following SCI (Anderson, 2004). Previous literature has revealed that there are several concerns related to sexual function for women with SCI. These include anxieties related to body image, self esteem, gender role, relationships, seduction, sexual confidence, sexual quality of life, and sexual satisfaction, all of which may be negatively influenced by urinary incontinence (Verschuren et al., 2010) and can have adverse effects on QOL.

Women's sexual dysfunctions following SCI have been greatly ignored in research for a number of reasons. A societal taboo regarding sexual dysfunction and sexual well-being, especially when associated with a chronic disease, has resulted in a deficiency of research in this area for all individuals (Verschuren et al., 2010). A related issue is the myth that individuals with disabilities vanquish their sexual selves and become 'asexual' beings (Ray & West, 1984). Singh and Sharma (2005) stated that sexuality is the issue that is most often neglected for women who have disabilities. Women make up a significantly smaller percentage of the individuals affected by SCI when compared to men (Westgren, Hultling, Levi, Seiger, & Westgren, 2007). Women account for just 20% of the population who are living with SCI and the remaining 80% of

individuals with SCI are male (Pentland, Walker, Minnes, Tremblay, Brouwer & Gould, 2002; Singh & Sharma, 2005). Consequently, research involving sexual dysfunction in women is even more scarce than for their male counterparts. Another reason that women with SCI have been overlooked in research regarding sexuality is the belief that women play a passive role during sexual activity. As a result of this attitude it has been misconstrued that women face fewer issues with sexual readjustment after SCI than men, and therefore, warrant less investigation (Ford & Orfirer, 1967). For men, SCI can result in erectile dysfunctions and infertility, but a woman's ability to conceive post-injury is largely unaffected. This has resulted in another misconception that a women's sexuality after SCI must also be unaffected (Benevento & Sipski, 2002; Singh & Sharma, 2005). Unfortunately, fertility and sexuality, though linked, are separate issues, and one should not be ignored because the other appears to be functioning well. Another possibility is the actual physical location of male versus female sex organs. A male's sex organs are located external to his body. This makes them more accessible and more easily studied as opposed to a woman's sex organs which reside internally and pose an additional challenge for investigators as examination of these organs would require a more invasive approach. A qualitative study involving 30 women with SCI by Pentland et al., (2002) revealed that the women under examination felt as though they had been ignored by health care professionals, and that no attempt to understand the concerns specific to women with SCI, especially sexual concerns, had been made. Women may be reluctant to ask for the specialized information they require as the majority of individuals around them in medical and rehabilitation settings will most likely be male (Scheele, 1988).

The objective of this paper is to examine the experience of sexuality for women who are concerned about urinary incontinence (UI) following SCI. This will be achieved by reviewing relevant literature and outlining the process of micturition, types of neurogenic bladders and resulting incontinence, current bladder management techniques, as well as characteristics of women's sexuality and QOL measures pre and post-injury. This paper will conclude with the methods for a proposed qualitative research study which will utilize phenomenological interviews to expose the stories and experiences of women who encounter this phenomenon in an attempt to answer the following questions: *What is the experience of sexuality for women who are concerned about UI as a consequence of SCI? What impact does UI have on sexual function and sexual satisfaction in women with SCI? and What are the main concerns regarding UI and sexuality for these women?*

1.2 The Process of Micturition

Micturition, or urination, can occur voluntarily or involuntarily. Voluntary control of micturition occurs when the sensation of a full bladder is conveyed to the brain. The brain, in turn, initiates contraction of the detrusor muscle that lines the bladder as well as the relaxation of the urethral sphincter, and a contraction of the abdominal muscles. When an individual is not toilet trained, he or she voids involuntarily as a result of spinal reflexes. Thus, micturition is largely controlled by a reflex process that can either be enhanced or inhibited by voluntary cortical control (Delehanty & Stravino, 1970). The actual mechanisms behind the process of micturition differ between that of an able-bodied individual, and an individual who has a SCI.

1.2.2 Individual who is able-bodied:

In an able-bodied bladder, the process of micturition involves the complete relaxation of the pelvic floor and external sphincter, followed by a contraction of the detrusor which compresses the bladder and stimulates the neck of the bladder to open (Shuttleworth, 1970). As the volume of urine increases, the bladder wall expands. When a volume of 150ml to 250ml is reached, stretch receptors in the detrusor muscle which lines the bladder send signals via the visceral afferent pelvic nerves to the micturition reflex center in the spinal cord between the second and fourth sacral segments (S2-S4). This sensory information then ascends the spinal cord to the midbrain and pons which are under voluntary cortical control and coordinate the actions of the nervous pathways. If it is an appropriate time to void, descending motor information will be sent to the motoneurons in the sacral region which cause the parasympathetic efferent fibers of the pelvic nerve to signal the detrusor muscle to contract. At the same time, signals from the spinal micturition center inhibit the pudendal nerve and result in a relaxation of the external sphincter which is otherwise closed. If it were perceived to be an inappropriate time to void, voluntary inhibition of the reflex could be achieved by constricting the external sphincter. Conditioning of the sphincter is the mechanism behind the process of becoming toilet trained (Delehanty & Stravino, 1970; Horton, Chancellor, & Labatia, 2003).

1.2.3 Individual who has a Spinal Cord Injury:

The term 'neurogenic bladder' refers to dysfunction of the urinary bladder as a result of damage to the nervous system, and is often associated with SCI (Delehanty & Stravino, 1970). Two types of neurogenic bladder exist, those being overactive and

hypotonic, and correspond with the level of damage to the nervous system. There are two types of detrusor over activity: neurogenic detrusor overactivity and idiopathic detrusor overactivity. They differ on the basis that the underlying cause is either known, or unknown, respectively (Karsenty et al., 2008; Sahai, Khan, Fowler, & Dasgupta, 2005). Neurogenic detrusor overactivity is common among individuals with neurological pathologies, including SCI (Schurch et al., 2005). In an upper motor neuron lesion, the sacral micturition reflex is maintained and the overactive bladder works reflexively. Thus, the bladder is emptied involuntarily when stretch receptors in the detrusor muscle reach their threshold, causing involuntary reflex contractions of the bladder and often leading to incontinence. However, due to spasticity in the external sphincter and detrusor, emptying of the bladder may be inadequate. (Delehanty & Stravino, 1970). In a lower motor neuron lesion, the sacral reflex center is often ablated. The bladder muscle loses tone and can no longer empty reflexively, resulting in a hypotonic bladder. Due to constant distension, the wall of the bladder becomes thin and loses sensation. In this state, the bladder can hold up to almost seven times the amount of urine as compared to an able-bodied bladder, however, the individual is unable to inhibit the frequent spilling over of urine, referred to as overflow leakage (Delehanty & Stravino, 1970; Hotron, Chancellor, & Labatia, 2003). In neurogenic detrusor overactivity, the pathways that provide inhibitory signals to the sacral micturition centre are disrupted, resulting in involuntary contractions of the detrusor, and in most cases, incontinence (Patel, Patterson, & Chapple, 2006).

With regards to urinary incontinence during sexual activity in women after SCI, those with overactive bladders will typically experience incontinence that is associated

with the muscle activity that occurs with an orgasm, while those with hypotonic bladders will experience incontinence that is associated with certain movements and positions during intercourse that place pressure on the bladder (Delehanty & Stravino, 1970).

1.3 Bladder Management Techniques

There are currently a number of treatments and strategies available for reducing the likelihood of incontinence from occurring during sexual activity including mechanical, pharmacological, and surgical treatments (Forsythe & Horsewell, 2006). The most popular mechanical strategy is catheterization, which allows urine to drain from the bladder (Shuttleworth, 1970). Examples of pharmacological treatments include anticholinergic medications such as Oxybutinine (Ditropan) that work by decreasing involuntary detrusor contractions. There are also antispasmodic medications such as Baclofen (Lioresal) that decrease spasticity which in turn reduces the number of pelvic floor spasms, increases bladder capacity, and reduces residual volume (Ochs, Naunamm, Dimitrijevic, & Sindou, 1999). Enterocystoplasty (bladder augmentation) is a surgical procedure that aids with urinary incontinence in which patches of tissue from other areas are used to enlarge the bladder (Cranidis & Nestoridis, 2000). The Mitrofanoff principle involves the diversion of urine via reconstruction through the appendix. One end of the appendix is fixed to the bladder wall. The other end is attached to the surface of the skin by way of caliber conduit at an area that is more easily accessible for those with motor impairments, and can be catheterized through a stoma. This technique also involves the use of a flap to prevent reflux, and relies on a positive-pressure gradient (Monti, Lara, Dutra, & Rezende De Carvalho, 1997.) Injections of botulinum neurotoxin type A (BTX-A), more commonly recognized as BOTOX®, into the detrusor muscle have been used to

inhibit acetylcholine (ACh) release from parasympathetic fibres by binding to pre-synaptic nerve endings and blocking intrinsic bladder reflexes (Reitz et al., 2004; Wefer et al., 2010). Acetylcholine is the primary neurotransmitter involved in the mediation of detrusor contractions. Therefore, the temporary chemodenervation results in a decrease or loss of neuronal activity at the target organ, as well as flaccid paralysis (Oeconomou & Aposotolidis, 2010; Reitz et al., 2004). The paralysis is temporary and reverses due to the resprouting of functional axons that reconnect pre-synaptic nerve endings with their target organs (Reitz et al., 2004). Botulinum neurotoxin type-A injections may be able to bridge the gap between oral medications and invasive surgical procedures (Patki, Hamid, Arumugam, Shah, & Craggs, 2006).

When managing neurogenic detrusor overactivity, first line treatments involve catheterization combined with medications (Do Ngoc Thanh, Audry, & Forin, 2009; Patel, Patterson, & Chapple, 2006; Patki, et al., 2006; Reitz et al., 2004; Sahai et al., 2005; Schurch et al., 2000; Schurch et al., 2005; Wefer et al., 2010), but due to the frequent occurrence of side effects that result from anticholinergic medications including dry mouth, constipation, blurred vision, drowsiness, and tachycardia (Sahai, et al., 2005; Wefer et al., 2010), the dosage that most patients are able to tolerate is not great enough to affect change, and many patients become non-compliant with treatment (Bagi & Biering-Sørensen, 2004; Patel, Patterson, & Chapple, 2006; Patki et al., 2006; Schurch et al., 2000; Schurch et al., 2005). Since surgical procedures may not be a viable option for all patients with SCI, it is possible for UI to continue to be problematic

1.4 Sexuality

Traumatic SCI most commonly occurs in young adults at a point in their lives when sexual activity levels and reproductive capacity are at their peak (Reitz, et al., 2004). A SCI will have an effect not only the spinal cord itself, but also on various organs and body systems, including those which are relevant to sexual functioning (Verschuren et al., 2010). There is noticeably more information available in the literature concerning men with SCI than women with SCI, especially regarding the topic of sexuality (Nygaard, Bartscht & Cole, 1990). Until this point, the various dimensions of a woman's sexuality including the psychological, social, emotional, and relationship aspects, as well as a woman's sexual responses, desires, and needs after SCI have been neglected, generating little or no scientific interest (Tepper, Whipple, Richards & Komisaruk, 2001). The primary focus of medical rehabilitation literature involving the sexuality of women with a chronic disability, including SCI, has been predominantly concentrated on female reproductive functioning. This includes topics such as menstruation, ovulation, pregnancy, the ability to care for a child, and the associated complications resulting from the disability. Thus, it appears as though a woman's sexuality is often viewed only as her ability to reproduce, and consequently, a women's sexuality has been portrayed as nothing more than child bearing (Charlifue, Gerhart, Menter, Whitneck & Scott Manley, 1992; Singh & Sharma, 2005; Tepper et al., 2001). Males often experience a loss of erection, ejaculation, and fertility after SCI whereas a woman's ability to become pregnant and give birth after SCI is almost unaffected. This has resulted in an assumption that a woman's sexuality after SCI must also be unaffected. Singh and Sharma (2005) concluded that although a woman's sexual function after SCI may be comparable to that

of an able-bodied woman, women with SCI do frequently experience sexual difficulties and obstacles both related and unrelated to child bearing. A discussion of the various dimensions of a woman's sexual life that are affected by SCI will follow and will include relationships, sexual desire, frequency, types of activities, stimulation and arousal, orgasm and sexual satisfaction.

1.4.2 Sexuality- Relationships

Spinal cord injury and its related consequences have a greater impact on the marital status of women than men (Singh & Sharma, 2005), and the marriage rate is considerably lower for women with SCI than it is for men with SCI, or able-bodied individuals (Pentland et al., 2002). A chart outlining the characteristics of the participants involved in six relevant research studies as well as their relationship statuses is included on page 35. Eighty-six percent of the women in Singh and Sharma's (2005) study who were not married at the time of their injury wished to get married, but only half of those women had found a partner and become married at the time of the study. The women who did marry were of a higher socioeconomic status, were highly educated and had adjusted well to their disability. Therefore, it appears as though individuals who reduce the impact of their disability on potential partners become more attractive from a relationship perspective than someone who has become dependent on others as a result of their disability (Milligan & Neufeldt, 1998).

Divorce is a legitimate concern for individuals with SCI, especially women, as the rate of divorce and separation post-injury has been reported to be almost double that of the rates for divorce and separation before an injury (22%, and 12%, respectively) (Charlifue et al., 1992). The phenomenological study by Tepper et al., (2001) revealed

that 11 of the 15 women included in the study were in committed relationships, either living with their partners or married, at the time of their injuries. Of these 11 women, eight considered SCI to play a key role in ending their relationships. It is possible for SCI to initiate growth within a couple's relationship but unfortunately, more often it becomes a stressor on the relationship (Verschuren et al., 2010).

1.4.3 Sexuality- Sexual Desire

Women's sexual desires have been found to decrease after SCI (Benevento & Sipski, 2002; Kreuter, Siösteen, & Biering-Sørensen, 2008; Reitz et al., 2004). For example, Charlifue and colleagues (1992) reported that in their study of 231 women with SCI, 46% rated sex to be less important after their injury than before. Likewise, Lysberg and Severinsson (2003) found that 25% of participants said that sexuality was less important after the injury than before. Sipski and Alexander (1993) stated that only 20% of women without a SCI reported having levels of sexual desire that could be described as low to none, compared to 44% of women with SCI who reported their sexual desire as low or none, and Kreuter and colleagues (2008) found that 51% of their participants felt that the importance of sex had decreased since their injuries. Regarding the relationship between sexual function and desire, the women with preserved sensation in the genital region described sexual activity to be more important than those women who experienced decreased genital or absent genital sensation. Although sexual desire seems to typically decrease after SCI, a large number of participants (72.5%) in the study by Singh and Sharma (2005) conveyed that they had an interest in sex, and that they understood the importance of engaging in sexual activity post-injury (87.5%). Despite this, 65% still reported a decrease in their desire for sex. On the other hand, some studies have shown a

continued importance of sexuality after SCI. For example, White, Rintala, Hart and Fuhrer (1993) found that 72% of their participants had reported engaging in sexual intercourse since the injury. Further, Kretuer and colleagues (2008) found that 38% of the women with SCI in their study reported having “great sexual desires” while Reitz and colleagues (2004) reported that of 16 women with SCI, 50% rated their sexual desire as high. When compared to the general population, individuals with SCI are, to some extent, less sexually active, but the numbers derived from the research presented above clearly demonstrates that the SCI population is by no means nonsexual and that women remain interested in sex post-injury, especially those women who have some amount of preserved genital sensation. Many women continue to understand the importance of sex in their relationships and in their lives.

1.4.4 Sexuality- Frequency

The frequency of sexual activity is also often reduced in women with SCI (Charlifue et al., 1992; Kreuter, Siösteen, & Biering-Sørensen, 2008; Reitz et al., 2004). Siosteen et al., (1990) found that in the 13 cases of women with SCI that were investigated, zero reported an increase in frequency of sexual activity, 50% reported no change, 33% reported a decrease in sexual intercourse, and 17% became completely abstinent. Lysberg and Severinsson (2003) reported that 25% of their participants had not developed a sex life post-injury, and Reitz et al., (2004) found that only 37.4% of their female participants had engaged in sexual intercourse since their injuries. One possible explanation for the decreased frequency of sexual intercourse, as well as a decrease in desire could be due to a purposive ‘shutting out’ of sexuality by women with SCI. This ‘shutting out’ of sexuality was found in the phenomenological study by Tepper et al.

(2001) and occurred as a result of women essentially 'shutting down' their sexuality because they believed they would no longer be capable of experiencing sexual pleasure due to a decreased or absence of sensation in the genital area. If women believe they will not feel pleasure from sexual activities, desire and therefore frequency may be affected. Another possible reason for the decrease in frequency of sexual activities in women with SCI has to do with a reduction in independence and social contacts. Hicken and colleagues (2001) compared matched cases of individuals with SCI versus individuals without SCI on a number of scales and questionnaires. They found that individuals who were bladder or bowel dependent had initiated fewer social contacts with strangers than those who were independent. Without making new contacts, the individual will not be meeting any new potential sexual partners and as a result, the frequency of sexual activity one participates in may be lower. Difficulty adjusting to body changes that one may experience in both appearance and function as a result of SCI may also have a negative effect on the frequency of participation in sexual activities. Difficulty adjusting may increase one's fear of rejection by a potential partner (Bregman & Hadley, 1976). If the individual has not yet themselves accepted their injury, they will most likely have difficulty expecting others to accept them. Consequently, he or she may avoid these types of situations all together to avert feeling rejected. Decreases in mobility, and thus a fear of no longer being able to perform sexual activities the same way one did prior to his or her injury may cause an individual with SCI to avoid sexual activities. In this situation, it would be beneficial if the individual had a partner with whom he or she felt comfortable exploring new sexual avenues. Lastly, the social stigma that individuals who have

disabilities are not sexual beings may also contribute to the decreased frequency of participation in sexual activities for this population.

1.4.5 Sexuality- Types of Activities

There may be little difference in the types of sexual activities that women participate in before and after SCI (Charlifue et al., 1992; Sipski & Alexander 1993), though certain sexual activities may be preferred after injury and include kissing, hugging, touching, and caressing (Kreuter, Siösteen, & Biering-Sørensen, 2008; Reitz et al., 2004; Sipski & Alexander, 1993). Genital caressing and sexual intercourse are likely to become less important for women after SCI, but sexual fantasies and thoughts about past sexual experiences prior to the injury, as well as being aware of all of one's senses becomes more important (Kreuter, Siösteen, & Biering-Sørensen, 2008). It is valuable for individuals with SCI to explore with their partners and discover new types of sexual activities that will be satisfying for both themselves as well as their partners. One example is to uncover new and effective erogenous zones that are unaffected by their injuries, such as the ear lobe (Kreuter, Siösteen, & Biering-Sørensen, 2008; Lysberg & Severinsson, 2003). Of the sexually active women with SCI in Kreuter and colleague's study (2008), 21% felt that their sexual repertoire was more varied after their injuries, 37% felt that it had not changed, and 42% felt that their sexual repertoires had dwindled. Ten of the 16 women in the Rietz et al., (2004) study stated that they participated in sexual activity on a regular basis. For three of these women, sexual activity involved masturbation, for seven of the women it meant kissing and caressing, and for six of the women it entailed sexual intercourse.

1.4.6 Sexuality- Stimulation and Arousal

The ability for a woman with SCI to become sexually aroused and display the physiological responses that are commonly associated with sexual arousal seems to occur less frequently after injury. More than half (53%) of the women in Kreuter and colleagues' study (2008) reported that they were less likely to become sexually aroused after their injuries. Physiological responses such as lubrication and clitoral swelling resulting from sexual stimulation (either intercourse or masturbation) occurred always in 60% of the women in the study by Reitz et al., (2004), most of the time in 20%, sometimes in 10%, and rarely in 10%. Physiological responses resulting from central stimulation that included audio and visual sources, or imagination were lower and only 50% of the women reported any physiological responses.

1.4.7 Sexuality- Orgasm

Sexual responses may differ based on the level of the injury and the severity of injury (either complete or incomplete). It is possible for women, even women who have complete SCI's, to experience an orgasm post-injury. In this case, the orgasm is thought to be attributed to a genital afferent pathway to the brain by means of the vagus nerves (Komisaruk et al., 1996). Siosteen, Lundqvist, Blomstrand, Sullivan and Sullivan (1990) found that in 13 women with SCI, zero women reported improved orgasm, 33% reported no change, 25% reported decreased sensation of orgasm, and 42% reported having no orgasm after injury. Tepper et al., (2001) conducted phenomenological interviews with 15 women who had SCI and found that 13 of the women had experienced orgasms prior to the injury, compared to only eight women who had experienced an orgasm since their injury. Benevento and Sipski (2002) found that 100% of women without SCI were able to

evoke orgasm in a laboratory setting compared to 52% of women with SCI who were able to do so. Reitz et al., (2004) found that of the 16 women in their study, 62% were still able to experience orgasm. Of the 16 women, three women often experienced orgasm, three occasionally experienced orgasm, and the remaining 10 had never experienced an orgasm since their injuries (only 10 had sex after injury). They also reported that the group who is least likely to experience an orgasm includes those who have LMN lesions that affect sacral segments. Significantly less of the women with SCI in the study by Kreuter and colleagues (2008) experienced orgasms most or all of the time when compared to age matched females who did not have SCIs (23% and 42%, respectively).

1.4.8 Sexuality- Satisfaction

Women with SCI will typically also experience a decrease in sexual satisfaction after injury (Kreuter, Siösteen & Biering-Sørensen, 2008; Reitz et al., 2004). Reitz et al., (2004) reported that 25% of the women in their study were completely satisfied sexually, 13% were sometimes satisfied, 31% were rarely satisfied, and 31% were never satisfied. Overall, in the study by Singh and Sharma (2005), 55% of the women with SCI stated that they were satisfied with their sexual experiences post-injury, however, 19 women described their sexual lives post-injury as worse than before their injuries. Kreuter and colleagues (2008) discovered that sexual satisfaction in women with SCI, which was reported in 51% of the participants who had a SCI, was lower than that of the able-bodied controls, of which 62% considered themselves to be sexually satisfied. What was interesting was the women with SCI reported having much higher levels of sexual satisfaction before their injuries (83%) than the controls without SCI (62%). The authors

suggest that this could be the result of glorification or memory bias of their sexual lives before the women incurred their injuries.

The sexual satisfaction of the partners of women who have SCI is another dimension of sexual satisfaction that may become even more concerning post-injury. The same study by Kreuter and colleagues (2008) found that 91% of the controls and only 66% of the women with SCI said they were able to sexually please their partners. However, 93% of the women with SCI recounted being able to satisfy their partners prior to their injuries. The study by Singh and Sharma (2005) also found that 15 of the 40 women who participated in the study felt that their partners were never satisfied with their sexual lives post-injury. It seems that women with SCI are less confident about their abilities to sexually satisfy their partners. This may cause them to pull away from sexual relationships as this perceived inability to please their partner may make the women feel inadequate. Sexuality is a human right and is an important contributor to a fulfilling life. It also plays an important role in shaping one's QOL.

1.5 Quality of Life

Quality of life is a complex concept. It is subjective and is based on individual values that differ from person to person. After a SCI, the various physical, psychological, social and financial consequences often affect a person's QOL, and this affect will differ based on the individual, the injury, what he or she views to be important, and his or her stage of life (Anderson, 2004). Though each person will have a different experience with SCI, after reviewing relevant literature, it has been consistently reported that individuals with SCI experience a lower QOL than that of an able-bodied individual. However, rarely have the individuals with SCI been asked how their QOL could be improved (Anderson,

2004). This seems to indicate that researchers have, until this point, only been investigating half of the issue by looking solely at the problem and ignoring any suggestions and important information that could possibly be provided by the identified population if given the chance. Anderson (2004) also suggests that even small improvements to important issues for individuals with SCI can still have tremendous positive effects on QOL.

The ability to make adaptations to one's sexual life after SCI is closely linked to QOL (Siösteen et al., 1990) and the outcome of one's overall life adjustment is very much influenced by the extent to which one's sexual rehabilitation is successful (Reitz, et al., 2004). Having an active and satisfying sexual life post-injury is associated with improved QOL and overall life adjustment (Siösteen et al., 1990). Elfström, Rydén, Kreuter, Taft, and Sullivan (2005) found that higher levels of acceptance in which the individual adapts to their injury instead of giving up, as well as lower levels of social reliance and depression predicted higher levels of health related QOL.

Self-efficacy refers to one's belief of confidence in their ability to successfully complete certain tasks and behaviours (Middleton, Tran, & Craig, 2007). Middleton and colleagues (2007) used the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) and the Moorong Self-Efficacy Scale to investigate the relationship between the QOL of individuals with SCI with self-efficacy and pain. They found that participants with SCI scored consistently lower on all eight domains of the SF-36 (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health) when compared to the general population. The domains of physical functioning, limitations to physical role, and pain seemed to be the areas that

were the most greatly affected by SCI, all of which may in turn have a negative effect on sexual function. They also found that women with SCI had a lower QOL than men who had SCI.

1.6 Psychopathology, Image, Esteem and Satisfaction

Human sexuality is multi-faceted and involves complex relationships between biological, relational, psychological and socio-cultural components (Verschuren et al., 2010). How one views his or her body, as well as how one believes others view his or her body is incredibly important to sexuality (Kretuer, Siösteen, & Biering-Sørensen, 2008). Psychosocial issues relating to sexuality and subjective measures including body image and sexual desire may be more important to women with SCI and have a greater impact on sexuality than physical concerns and preserved sexual abilities (Reitz et al., 2004; White, Rintala, Hart, & Fuhrer, 1993).

When comparing women with SCI to age matched controls, Kretuer and colleagues (2008) found that 62% of their controls considered themselves to be rather or very attractive, whereas only 41% of the women with SCI felt that they were rather or very attractive. One-third of the women with SCI felt that other people considered them to be less attractive women as a result of their injuries, and this feeling was demonstrated as only 41% of the women with SCI thought they were attractive, but when asked about their feelings of attractiveness before their injuries, 74% had considered themselves to be rather or very attractive women.

Women with SCI may have improvements to their feelings of self-esteem after SCI more promptly than to their sexual-esteem as stated in Tepper et al., (2001), and the delay in sexual-esteem can also negatively affect one's sexual satisfaction. Having a high

self-esteem does not necessarily mean that other areas of one's esteem, such as body-esteem or sexual-esteem will have the same response nor that those feelings will carry over into other life areas. Tepper and colleagues (2001) suggest that increases in sexual-esteem often precede sexual pleasure and orgasm after SCI. A study involving urinary diversion and catheterization through an umbilical stoma found that as the women in the study who were sexually active began to feel happier with their body image (scoring 3 to 6 points higher on a scale which rated 1 as very unhappy and 10 as very happy), the frequency of sexual intercourse increased (increases were anywhere from one to seven times more frequent per month) (Moreno et al., 1995). In this study, not only was the frequency of sexual intercourse increased and associated with an improved body image, but the women who were sexually active also reported higher subjective levels of sexual pleasure. Increased levels of confidence and esteem due to an improvement in body image may allow women with SCI to enjoy their sexual experiences more freely, and thus, result in increased levels of sexual satisfaction.

White, Rintala, Hart and Fuhrer (1993) assessed multiple areas of concern for women following SCI. Of the 17 areas identified, sexual satisfaction and feelings of unattractiveness were ranked as the third (not satisfying a partner), fourth (feeling sexually unattractive), fifth (being viewed as sexually unattractive by others), and sixth (not being personally satisfied) most concerning areas. Fifty-two percent of the women in the study expressed concerns regarding an inability to sexually satisfy their partner, 51% of the women felt sexually unattractive, 51% of the women were also concerned that others would find them sexually unattractive, and 45% of the women displayed concerns that they were not sexually satisfied enough themselves. This study also ranked the

importance of 12 life areas, as well as satisfaction with those areas. The women presented the life area 'sex life' to be relatively unimportant by ranking it tenth in importance out of 12 possible areas. Interestingly enough, sex life had the same ranking position as tenth out of 12 for satisfaction. Perhaps sex life was ranked lower in importance for these women because they were not satisfied with their sexual lives. It may be possible that if their levels of sexual satisfaction were higher, they would rank the importance of their sex lives to be higher as well instead of just losing interest.

Taleporos, Dip and McCabe (2002) measured depression, anxiety and stress (Short Form Depression, Anxiety and Stress Scale (DASS)), self-esteem (Rosenberg Self-Esteem Scale), sexual-esteem (Short Form Sexual-Esteem Sub-Scale in the Sexuality Scale by Snell and Papini (1989)), as well as body-esteem (Body-Esteem Scale), and sexual satisfaction (a single item inquiring about sexual satisfaction over the past six months measured on a seven point Likert Scale). In total, 1196 participants comprised of both men and women, with and without disabilities were included in the study. It was discovered that high levels of body-esteem and sexual satisfaction in participants with physical disabilities were associated with higher levels of self-esteem and lower levels of depression for those individuals. Women with physical disabilities in particular demonstrated a stronger link between body-esteem and self-esteem. The authors suggest that this could be primarily due to a pressure for women to conform to certain standards and expectations of a woman's beauty that have been accepted within our society. Overall, it was concluded that body-esteem, sexual-esteem and sexual satisfaction were robustly influential on self-esteem for individuals with physical disabilities. Sexual satisfaction, high levels of sexual-esteem, and high levels of body-

esteem were predictors of higher levels of self-esteem. Sexual satisfaction and high levels of body-esteem were associated with lower levels of depression. Lastly, it was concluded that sexual well-being and body-esteem had a stronger impact on the overall psychological well-being for the participants who had physical disabilities than for the participants who were able-bodied. Therefore, it appears as though some of the issues relating to depression and lower levels of self-esteem for people with disabilities are controlled by their negative feelings about their bodies and their sexual lives. The results for the scales of anxiety and stress did not show the same type of relationship with sexual satisfaction, sexual-esteem, and body-esteem as depression and self-esteem. A possible explanation could be that the measures of anxiety and stress are not considered as relevant to one's self worth as depression and self-esteem.

Verschuren et al., (2010), state that body image may be negatively affected by chronic diseases, which would include SCI, by causing changes to one's appearance that may be regarded by others as abnormal, as well as a loss of control over one's own movements and basic functions. In some cases, the accidents causing SCI may also result in disfigurement which can bring about insecurities regarding the image of one's body. Often times, a loss of control over one's own movements whether it be the inability to inhibit unwanted movements such as spasticity, or an inability to produce a desired movement resulting from paralysis will accompany SCI. Body image can be negatively impacted by this loss of control over one's movements as the individual may be unable to participate in activities that used to give them confidence in their appearance and body image, for example, exercise. A loss of control over one's basic functions, such as bladder and bowel control is also commonly experienced after SCI. Urinary or bowel

accidents and incontinence can also have a negative impact on body image as these body functions are often thought of as unpleasant and are associated with other negative connotations including poor hygiene. If the individual feels that they have lost control of their body, their connection to it may become weakened, and their feelings of body esteem and positivity towards their body image will decline which in turn, can have negative effects on sexuality.

1.7 Conclusions

Currently, the literature concerning urinary incontinence and women's sexual function seems to have been analyzed separately. Both neurogenic bladder following SCI and women's sexuality after SCI have been examined to some extent, but they have yet to be studied and considered together. Future research needs to bring these concepts together to begin to understand the relationship between urinary incontinence and sexuality after SCI for women, and how urinary incontinence affects a woman's sexuality after SCI. This will allow researchers and healthcare professionals to develop appropriate strategies, therapies, and treatments to effectively target the concerns of women with SCI. We know that both urinary incontinence and sexuality are among the top priorities and major concerns for this population. We now need to determine the meaning that this phenomenon has for these individuals so researchers can work towards making improvements in this ignored but, invaluable area of life.

Previously, the focus after SCI has been on survival, but as that rate continues to rise (Schurch et al., 1996), and the life expectancy of individuals with SCI almost matches that of able-bodied individuals due to advancements medical and rehabilitative therapies, it is imperative that the focus shift away from just surviving, to surviving and

living with a higher QOL (Patki et al., 2006; Verschuren et al., 2010). Research in the near future should not only be focused on finding a ‘cure’ for SCI, but should also focus on the more realistic task of improving the QOL for individuals who are living with SCI (Anderson, 2004). This should be achieved by developing treatments to target areas of life, such as bladder control and sexuality, which have been identified as top priorities for the SCI population. Research and advancements in the therapeutic treatment of neurogenic detrusor overactivity as well as a better understanding of women’s sexuality after SCI and the relationship between the two has the potential to drastically improve the QOL for individuals who have sustained a SCI.

Chapter Three- Methods

Research Context

This research study which examines the experience of sexuality for women concerned about UI following SCI has been completed as a Master's thesis project in the Faculty of Applied Health Sciences at Brock University in St. Catharines, Ontario, Canada. To the researcher's knowledge, no study has been completed that examines specifically the connection between sexuality and UI. However, based upon previous literature it seems appropriate to consider an interrelationship between these two topics which is the rationale for the present investigation. Both sexuality and UI have been identified as top priorities to this special population (Anderson, 2004), so research involving the two issues has the potential to contribute a great deal of information that may be helpful in improving QOL. This study will examine the lived experiences of women who have firsthand knowledge of this phenomenon by means of in-depth interviews.

Theoretical Perspective

Researchers have their own beliefs and worldviews that guide both the design of their studies and the presentation of their results. Qualitative researchers should make their own personal biases explicit upfront and be aware that their assumptions will, to some extent, influence the investigation (Creswell, 2007). The worldview that I operate under is postpositivism. According to Creswell (2007), those who utilize this belief system typically use methods that resemble a more scientific or quantitative approach and involve logical steps, rigorous methods, and multiple perspectives. The work of a postpositivist is often presented in a way that resembles a scientific paper.

Methodology

Qualitative Research

Qualitative data is ideal for this type of project as one's experiences and concerns cannot be captured through questionnaires, nor can they be quantified and represented by a single number. Due to the personal nature of this topic and the value attached to this phenomenon, sensitivity and in-depth, detailed descriptions of the lived experience is both warranted and necessary.

Phenomenology

Phenomenology is a type of qualitative research that is utilized when attempting to understand the lived experiences of individuals who have firsthand knowledge of the phenomenon under investigation (Liamputtong, 2009). Phenomenology considers how one experiences the consciousness (Giorgi, 2009), and realizes the importance of bringing these experiences to light as no phenomenon will ever be experienced in the exact same way for any two individuals (Van Manen, 2001). The phenomenological methodology is not comprised of a specific set of procedures, steps or techniques. It is instead a way of thinking and it is carried out in a manner that is suitable for each particular research inquiry and the individuals that are involved in that investigation (Van Manen, 2001). Phenomenology hopes to capture the essence, or the meaning of the phenomenon, before social and/or cultural meanings are attached to it so it can be considered holistically across various contexts and situations (Giorgi, 2009).

Phenomenology most often utilizes in-depth interviews to obtain rich and detailed descriptions of people's lived experiences. Since every description of an experience has

already undergone some amount of interpretation, the objective is to obtain descriptions that represent that actual experience as closely possible (Van Manen, 2001).

There are two main phenomenological approaches: descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology. Descriptive phenomenology aims to describe, as accurately as possible, the lived experience of a phenomenon for the individuals under investigation with little interpretation, whereas interpretive phenomenology intends for the researcher to interpret informant information. The latter requires that the researcher have his or her own personal experience with the phenomenon, and it is that understanding that allows the researcher to interpret the meaning of the experience (Cohen & Omery, 2004). Since the researcher of the present study does not have her own personal experiences with this particular phenomenon as she does not have a SCI, she has employed the descriptive phenomenological approach.

The Interview

The interview is a verbal exchange of information that is useful for obtaining knowledge about phenomena that cannot be observed (Patton, 2002). Kvale (2007) states that an interview is a conversation in which views are exchanged on a topic of discussion between two people. An interview allows the individual to communicate his or her experiences in his or her own words, and allows the researcher to enter the participant's lived world (Kvale, 2007). Building rapport and establishing a relationship between the researcher and the participant where trust exists is fundamental for creating an environment where the participant feels willing to share important information (Speziale & Carpenter, 2007).

Data Collection Procedures

Sampling Criteria

Purposeful sampling was utilized as only certain individuals would be knowledgeable on the topic under investigation, and only these individuals would be able to provide information on the phenomenon valuable for this research inquiry. By selecting information-rich cases, the researcher was able to obtain very detailed information regarding the issues under investigation (Liampittong, 2009).

Phenomenological studies typically utilize a relatively small number of participants (Polit & Hungler, 1995). Polit and Hungler (1995) suggest including fewer than 10 informants in this type of study, and Smith and Osborn (2008) recommend three to six participants for a student project. A small sample size will allow the researcher to explore the topic in more depth and detail (Patton, 2002). The goal is to ensure a sample size large enough to examine patterns between informants, but to avoid a sample size so large that it creates an overwhelming amount of data. There is no concrete answer as to how many participants this type of study should incorporate (Patton, 2002; Smith & Osborn, 2008), but based upon the previous information, seven participants were included in this study.

The participants were required to fulfil specific inclusion criteria. Since research regarding sexual function after SCI has been predominantly focused on men, the current study chose to focus on women's experiences of sexuality after SCI and therefore, participants of this study were required to be female. The level and severity of SCI injury for inclusion to the study were not specified, and the study was open to including any woman with SCI. There were no specifications regarding the classification of SCI for two reasons. First, to the researcher's knowledge, the experience of sexuality for women

concerned about UI has not yet been investigated. Consequently, there were no existing guidelines to follow, and including a wider variety of injuries had the potential to determine which women have the largest concerns about the effects of UI on sexuality, and may help to identify where future research should focus its efforts. Second, due to the sensitive and private nature of the topic, recruiting participants willing to share their personal experiences was challenging. The researcher was happy to include any woman willing to share her experience in the study. Every woman's story contains useful information as her experience with the phenomenon will be different from any other woman's experience with that same phenomenon. Due to the mature nature of both the topic of interest and interview questions, participants were required to be the age of majority or older. To learn what effect UI may have on the experience of sexuality, the participants needed to either experience UI, or be a concerned about UI in a way that she felt affected her sexuality. In summary, participants included in the study were required to meet the following criteria: be female, 18 years of age or older, have a SCI, and experience UI, or a concern for UI that has a perceived effect on sexuality.

Recruiting Procedures

Participants were recruited by means of recruitment posters which were placed in the Neuromuscular Acquisition and Rehabilitation Lab at Brock University, and by word of mouth through referrals from other participants (a copy of the recruitment poster can be found in the data manual at the end of this document). The researcher did not initiate any conversation regarding the study in the rehabilitation lab at Brock University. All of the potential participants either approached the principle student investigator themselves in the lab, or contacted Dr. David Ditor by telephone at the phone number listed on the

recruitment poster. Any woman who inquired about the study and who displayed interest in participating was contacted by the researcher via telephone. The phone numbers for the potential participants were already available to the researcher as they were either on file in the lab, or had been previously acquired by Dr. David Ditor. In the initial telephone conversation, the researcher introduced herself and provided a brief overview of the study (a copy of the telephone script can be found in the data manual at the end of this document). If the potential participant expressed a desire to learn more about the study, she was asked a few introductory questions to gauge her suitability for the study. The women were told that they could refuse to answer any of the introductory questions if they wished, but that doing so would preclude them from participating. Specifically, each potential participant was asked her age and if she experiences UI, or a concern for UI that she feels affects her sexuality. Only those women that answered yes to both questions were allowed to continue on with the informed consent process. If the woman met the criteria for the study, and was still interested in participating, an interview time and location were agreed upon.

Prior to beginning the interview, the participants were told the details of the study and that they would be asked a series of open-ended questions that would allow them to fully describe their experiences with UI and sexuality. Participation in this investigation was strictly voluntary. The women were told that the interview would last approximately 90 to 120 minutes, that they could refuse to answer any questions that made them feel uncomfortable and they could withdraw from the study at any time with no consequence whatsoever. For those women that exercised in Dr. Ditor's Neuromuscular Acquisition and Rehabilitation Lab, it was made particularly clear that withdrawal from the study

would not affect her ability to continue exercising in any way. Potential participants were also told that their interview would be audio recorded so the researcher could revisit their answers during the data analysis phase, and that only the student researcher and the principal investigator would have access to the audio recordings. The participants were informed that the recordings would be destroyed upon the completion of the analysis of their content. Participants were told that the results of this study may be published in a scientific journal and/or presented at a scientific conference, but that their name would never be used in any form of dissemination; rather pseudonyms would be used when necessary. The participants were told that they would have the opportunity to review the researcher's notes immediately after the interview, and that upon request they may view the entire interview transcript when it was ready (approximately 2 months after their interview). All potential participants were given a letter of invitation and an informed consent form which outlined the following details: the purpose of the study, requirements of participation and the rights of the participant, to assist the potential informant in making an informed decision regarding her participation in the study (a copy of the letter of invitation and informed consent form can be found in the data manual at the end of this document). The participants had a chance to ask any remaining questions to the student researcher and/or the principal investigator before signing the informed consent form.

Sample

Every woman who inquired about the study agreed to participate. All seven of the participants were Caucasian and were Canadian with European descent, except one woman who was born in Syria. The age range of the participants at the time of injury was

18-59 years old, and the age range at the time of the study was 24-61 years old. The average interview length was 85 minutes. Table 1 depicts further demographic information on the women and their interviews. Table 2 provides more information on sexuality and relationship characteristics of the women.

Table 1: Demographic and Interview Characteristics

Participant #	Pseudonym	Age	Education (highest degree obtained)	Occupation	Injury (level)	Injury (severity)	Time Post-Injury	Interview Length & Location
1	Mary-Cat	61	Some University	City Hall (Retired)	C5	Incomplete	34 years	95 minutes; Informant's home
2	Caroline	31	University Degree	Self-Employed: disability awareness	T1	Complete	13 years	68 minutes; Informant's home
3	Brooke	24	Some Graduate Studies	Graduate Student	T6	Complete	3 years	108 minutes; Informant's home
4	Clay	34	University Degree	Brock University: administrative assistant	T4	Complete	16 years	98 minutes; Brock University
5	Sarah	30	High School Degree	Unemployed	C5	Incomplete	12 years	110 minutes; Informant's home
6	Jessica	59	Some High School	Department store (Retired)	L3	Incomplete	< 1 year	54 minutes; Brock University
7	Tina	28	High School Degree	Unemployed	T5	Complete	2 years	59 minutes; Brock University

Table 2: Participant Relationships & Sexuality

Participant #	Sexual Orientation	Current Relationship Status	Relationship Status at Time of Injury	Sexual Difficulties Prior to Injury	Participation in Sexual Activities Prior to Injury	Participation in Sexual Activities Post-Injury	Children: Prior to or Post Injury
1	Heterosexual	Single (divorced)	Married	Reported difficulty reaching orgasm	Yes	Kissing	2 (prior)
2	Heterosexual	Married	Casual Relationship	None Stated	Yes	Sexual Intercourse	1 (post)
3	Heterosexual	Single	Long Term Relationship	None Stated	Yes	Sexual Intercourse	None
4	Heterosexual	Engaged	Not Stated	None Stated	Yes	Sexual Intercourse	None
5	Heterosexual	Committed Relationship	Long Term Relationship	None Stated	Yes	Sexual Intercourse	1 (post)
6	Heterosexual	Married	Married	Rape	Yes	None	2 (prior)
7	Heterosexual	Married	Married	None Stated	Yes	Sexual Intercourse	3 (prior)

Ethics

All ethical guidelines as outlined in the Tri-Council Statement: Ethical Conduct for Research Involving Humans as described in Brock University's Faculty Handbook on research ethics was adhered to. The researcher completed and submitted an ethics application to Brock University's Research Ethics Board (REB) which was accepted on August 26th 2011 (File number 11-024) (a copy of the REB letter of approval can be found in the data manual at the end of this document).

Participant information was used only for the purpose of the investigation. Identifying information was known only by the student researcher and principle investigator. Any other people involved in the research study (thesis committee members) were aware only of the pseudonyms of the participants which ensured confidentiality and made certain that identifying information was unable to be linked to data collected. Participants were made aware that participation was completely voluntary, and were informed of their right to refuse answering any questions that made them feel

uncomfortable, and of their right to withdraw from the study at any time with no penalty. They were notified of these rights verbally during the initial telephone conversation, these rights were reiterated in the letter of invitation and the consent form, and stated one final time at the initiation of participant interviews. For those women that were currently exercising in Dr. Ditor's Neuromuscular Acquisition and Rehabilitation Lab, it was made particularly clear that withdrawal from the study would not affect her ability to keep exercising in the lab. The participants had the opportunity to ask any further questions to the student researcher and the principal investigator before signing the informed consent form. Data collected was kept in a locked file which was accessible only to the student researcher. Audio-recordings were deleted and destroyed upon completion of the study. Written data and interview transcripts were shredded and disposed of upon completion of the study.

Data Collection

Interviews

When utilizing phenomenology, the primary source of data collection is generally in-depth interviewing of people who have first-hand experience with the phenomenon (Patton, 2002). Each of the seven participants completed one in-depth interview lasting between 54 and 100 minutes in length. The average interview time was 85 minutes. All interviews were completed in one sitting with the exception of Participant Four who completed her interview in two parts due to schedule availability. Before the commencement of any interview, the participant was required to sign two copies of the informed consent form. One copy was kept by the participant for her own records, and the other copy was kept by the student researcher who conducted the interviews. Three of

the seven interviews took place at Brock University in Welch Hall. This meeting room was protected by a code lock and was closed to other students and Faculty during the time of the interviews. This ensured privacy between the interviewer and the informant, as well as provided an environment that was free of distractions. For the remaining four participants, interviews were conducted in their homes in a quiet and private space. This option was made available to every participant to avoid any issues with transportation and travel. The interviews were audio recorded using an Olympus Digital Voice Recorder VN-4100PC which was placed on a table between the interviewer and the informant. Participants were told that they could take a break during the interview if needed, and one participant required a break to use the washroom.

The interviews utilized mixed methods involving a standardized open-ended design combined with an interview guide approach. All informants were asked the same standardized open-ended questions to address specific topics of interest, and the emergent design flexibility of the interview guide approach allowed the student researcher freedom to pursue and explore more deeply, any relevant and important topics that arose that had been unanticipated or unplanned (Patton, 2002). Probe questions were employed to obtain more information regarding particular topics. This resulted in a more detailed account of how these women experienced this particular phenomenon, and no two interviews were exactly the same. Interview questions included the six types suggested by Michael Quinn Patton (Qualitative Research & Evaluative Methods, 3rd ed, 2002, pg. 348-351). Specifically, interview questions spanned the following six categories: demographic, experience/behaviour, knowledge, sensory, feeling/emotion, and opinion/value questions. An example question from each category with two probe

questions for each follows, and the complete interview guide can be found in the data manual at the end of this paper.

Demographic: Let's discuss a little bit of background information about both yourself, and your injury.

Probe Questions:

- What is your age?
- What is the level/ classification of your injury?

Experience/Behaviour: Describe the absolute worst situation with urinary incontinence. It can be either the worst experience that has actually happened to you, or a description of your worst case scenario regarding urinary incontinence.

Probe Questions:

- What is your biggest concern regarding UI?
- In your experience, what factors do you find increase your likelihood of experiencing UI? What factors have you been educated about that may increase your likelihood of experiencing UI?

Knowledge: What resources are you aware of that are available to help educate you on the topics of women's sexuality and/or urinary incontinence after spinal cord injury?

Probe Questions:

- To what extent is information literature, pamphlets, support groups etc. that discuss sexuality and/or UI available for individuals after sustaining a SCI? Do you feel the amount of resources regarding these topics is adequate?
- To what extent are these resources targeted towards women as opposed to men?

Sensory: Since your injury, what body issues are you, or would you be concerned about when participating in, or thinking about participating in sexual activities?

Probe Questions:

- Have you experienced UI since your injury?
- To what extent is UI a concern for you?

Feeling/Emotion: In which relationships have you experienced feelings of disappointment or frustration (regarding sexuality or urinary incontinence) since your injury?

Probe Questions:

- Have you felt any disappointment or frustration in your sexual relationships since your injury? Explain.
- To what extent are your Doctors/health-care providers knowledgeable on the topics of UI and sexuality in women with SCI?

Opinion/Value: Talk about your attitude towards sexuality and what it means for you to be a sexual person both before and after your injury. How has having a spinal cord injury changed or expanded that?

Probe Questions:

- Tell me about your sexual activity before your injury.*
- Would you say that your current level of sexual desire and sexual interest is higher, lower, or equal to that prior of your injury? Explain.*

The researcher had attended a formal training session for phenomenological interviews prior to the start of this research study. As a result, the researcher was aware of the format and procedure to follow during an interview, efficient probe questions for gaining additional information, and effective ways to handle informant emotions should the discussion evoke them. Contact information for the Canadian Paraplegic Association and Distress Centre Niagara were on the Letter of Invitation and Consent Form for the study. The student researcher also had the phone numbers for the organizations on hand during the interview. Participants would have been able to call either of these organizations during or after the interview if they became distressed as a result of the interview. This was made clear to the participants during the informed consent process, and both before and after the interview. None of the participants contacted either of the organizations during their interviews, and to the knowledge of the researcher, none of the women contacted either organization post-interview.

Field notes were made during the interviews that recorded any areas of interest to revisit later in the interview, any information that stood out as important or that had been repeated by the participant, and any forms of non-verbal communication. The participants were given the option to see the field notes at the conclusion of their interview to ensure

that none of their responses or non-verbal communication had been misinterpreted, but none of the women took advantage of the said opportunity.

Data Analysis

Transcription

Data analysis begins with ‘within-case’ analysis, and each interview is treated individually as its own case. The first phase of data analysis was to transcribe the interviews. This process involved listening to each of the audio recorded interviews, and typing exactly verbatim everything that had been said. Long pauses in speech, laughter, etc. were also noted in the transcripts.

Read and Jot

The second phase of data analysis was to read through each of the interview transcripts. While doing so, the researcher made note of information that stood out, or that appeared to be important. During the “read and jot,” the research became familiar with each of the transcripts, as well as the information that was contained within each one. While reading for the whole, the researcher was in pursuit of obtaining a *sense* of the entire description (Giorgi, 2009).

Meaning Units

The next step was to determine meaning units within each interview transcript. This serves to break long descriptions into smaller parts that are easier to work with and transform, and is achieved by marking the data whenever there is a shift in topic or meaning (Giorgi, 2009). This resulted in meaning units that were anywhere from a few

words to a few sentences in length. An example of the analysis is provided at the end of this chapter.

First Transformation

In the first transformation of the meaning units, first person narration was removed from the text and was replaced with P1 (participant 1), P2, P3, etc. Characteristics of natural speech that were not relevant to the meaning of the dialogue, such as the use of the word “umm,” were also removed. In this phase, the raw data was transformed into expressions that were more meaningful and that were suitable for phenomenological description (Giorgi, 2009).

Specific Descriptions

Next, the meaning units were re-assembled into specific and technical descriptions of the responses for each question. At this point, within-case analysis was still in effect, so a specific description of the information that was provided was created for each question, for every informant.

General Descriptions

The last phase of the within-case analysis was the formation of a general description for each interview transcript as a whole. The specific descriptions of the answers for each question within an interview were compiled, and technical, field specific terms were removed to create a general description of each interview. The general descriptions were condensed by retaining only the information that was specifically related to the research question; only information that pertained to either sexuality or UI, or both remained in the general descriptions. All other information was

removed from the general descriptions (though it could still be found in the ‘specific descriptions’).

Revelatory Phrases

After each interview had been analyzed separately as its own case, the cross-case analysis began and all of the interviews were considered collectively. The first step in the cross-case analysis was to highlight the revelatory phrases regarding sexuality, UI, and those topics blended together that could be found in all of the interviews. Revelatory phrases were those phrases which contained key words and strong idioms.

Emerging Themes

The last phase of analysis was to utilize the revelatory phrases to discover themes and patterns within the information that had been provided by the informants. Major themes were established under the categories *sexuality*, *UI* and *blended* (a combination of both sexuality and UI). When an idea had been brought up by the women multiple times, it became a theme and was discussed with a description of the meaning of that theme, and then supported by its founding quotes from the women. Five additional themes were identified that did not fit directly into one of the existing categories *sexuality*, *UI* or *blended*, but they have been presented in the same manner in the discussion section of this paper along with the reasons why that theme is relevant to the research question. These themes represent the lived experiences and main concerns of these women regarding this particular phenomenon.

Example:**Excerpt from the transcript of participant #2 (Caroline) with meaning units:**

Informant: Ok. Umm well we can start with how the spinal cord injury has changed that a little bit I think./ Um, I think it forced me to be more... (pause) to explore a little more. About how to be sexually satisfied/ because you know sensation has changed and all that kind of stuff/ and the ability to be spontaneous has changed a little bit./ Umm... (pause) but ahhh my sex life is still great./ we still have you know lots of sex (laughing)./ We are happy/ we have been together for 10 years/ and so that is you know that's kind of a good thing I guess after ten years of marriage./

Table 3: Analysis Example (Meaning Units, First Transformation & Specific Description):

Meaning Units	First Transformation	Specific Description
Ok. Umm well we can start with how the spinal cord injury has changed that a little bit I think.	P2 states that she will start by discussing how her SCI has changed the meaning of sexuality for her.	P2's SCI has forced her to do more exploring about how to be sexually satisfied. Though sensation and the ability to be spontaneous have changed since her injury, P2 says that her sex life is still great and that her and her husband still have a lot of sex. P2 states that her and her husband are happy, and that she thinks it is a good thing that they continue to be happy and have a lot of sex after 10 years of marriage.
Um, I think it forced me to be more... (pause) to explore a little more. About how to be sexually satisfied	P2 states that her SCI has forced her to do more exploring about how to achieve sexual satisfaction.	
because you know sensation has changed and all that kind of stuff	P2 states that her sensation has changed since SCI.	
and the ability to be spontaneous has changed a little bit.	P2 states that the spontaneity of sexual activity has changed since SCI.	
Umm... (pause) but ahhh my sex life is still great,	P2 states that her sex life is still great.	
we still have you know lots of sex (laughing).	P2 states that her and her husband still have a lot of sex.	
we are happy	P2 states that her and her	

	husband are happy.	
we have been together for 10 years	P2 states that her and her husband have been together for 10 years.	
and so that is you know that's kind of a good thing I guess after ten years of marriage.	P2 states that it is a good thing her and her husband still have a lot of sex and are still happy after 10 years of marriage.	

Chapter Four- Results

General Descriptions

The following are the general descriptions that have been derived from the information regarding sexuality and UI that was conveyed by the women as expressed in their interview transcripts:

1. Mary Cat

P1 has never been 100% comfortable with herself in sexual situations, and she describes herself as sexually “naive.” She says this because of her perceived lack of experience as her husband has been her only sexual partner. She says she was lacking creativity and the ability to pull from other experiences when she became paralyzed because there were no other experiences, and she would have liked to have been more experienced in that field. Her parents did not discuss sexuality with her, and gave her a book called “Esmerelda” to address the topic. When she arrived home after the injury, she was trying to adapt to her new life and she did not think about sex for the first year. She was nervous to try having sex because if she could not do it right, she did not want to do it at all, but she did eventually have sex with her husband. Though some movement was coming back and their water bed was helpful, she says that sex was “awkward.” She was afraid that she would be incontinent if they had sex, and she was in the beginning. It was embarrassing for her and it was extra work to get cleaned up and change the sheets, so that did not make sex fun. It took so much to be in rhythm that it was more effort than it was worth, and putting so much effort on trying to perform made it so sex was no longer enjoyable. If she did the pros and cons of it, it was more work than it was enjoyment. She says that she did not think their sex life was great, and neither did her

husband because they are not married anymore. It was always hard for her to reach orgasm and she felt like she was not achieving what she was supposed to, or doing what it was all about and that made her feel like a failure. It was always in the back of her mind that maybe it would happen, but she felt like she was missing out.

For P1, sexuality has to do with being appealing in the eyes of men. She is not interested in a relationship right now and being single is a preference because it would be too much work. She is not willing to go through the emotions of a relationship, and her bladder is much worse than it used to be so going down that road is not even a thought. Her fear of UI killed her sexuality because being incontinent while being intimate is not something that she is willing to compromise on. She is uncomfortable having a sexual relationship knowing that she will be incontinent, and even meeting Prince Charming would not change her mind because to her, it is not acceptable. Even if the person was very understanding, it would not make a difference because they are her thoughts that she has to deal with and she is “not in a good place” about her bladder right now. She does not miss or need a relationship in her life because she has other things going on and she does not consider herself to be a highly sexually motivated person.

She has not participated in a lot of sexual activity since her injury. She says that her ex-husband is a good person and that they stayed together for five years after the accident, but they had very limited romance. She says it is important not to have high expectations that things will be the same sexually as they were before, because they won't. She says you have to be flexible and willing to experiment. You must be honest and if something is not working, do not take it as a slap in the face, try something else.

The accident was a huge strain on her husband and he began drinking and using drugs, and then they divorced. The divorce was not fully because of the SCI, and had to do with other factors such as getting married too young, immaturity and her husband not being ready to commit. The accident just “put him into overload.” He stopped work and they had no income at the time. She will be forever grateful to him because he gave her his all to get her back on her feet, but it lead to his demise. Because she married so young, it was hard for her to get back in the field when her marriage ended. She had two short relationships after her divorce that were becoming sexual, but she was never comfortable enough to “go the last mile.” She feared that she would not be able to satisfy her partner, and that UI would happen. She says UI is beyond embarrassing. It is disgusting so she does not want to experience it during sex because it would take away from the joy of the experience. When one of those short relationships ended, the man became unreasonable and said that he was going to be with a “real woman” which had a negative effect on her self-esteem As for the other short relationship, she was shocked when the man approached her and said that he had been meaning to talk to her. He was smaller than she was physically and she felt like she overpowered him, so the relationship ended. She came to think that relationships were not worth it, and filled her time with other things. She has not had a relationship in over 20 years and would maybe like to have someone to talk to and do things with, but nothing beyond that because she is not willing to compromise her time. She likes her life the way it is. She did not have any feelings of disappointment or frustration in the two short relationships because they were just to see if she was still “attractable to the male species.”

She does not take medications that affect sexuality, but takes medication for both her bladder and bowels. She is definitely concerned about her bladder issues which she has had from the beginning and calls “embarrassing.” She thinks her bladder issues have a lot to do with nerves and ever since she decided not to worry about it and adopt the mentality that whatever happens, happens, her bladder has improved leaps and bounds. She states that she can take the train to Toronto without worrying about it. She says her bladder is not good at night because she is tired and does not wake up so she is incontinent 98% of nights. She says it is a pain [nuisance] and a lot of work, but that it could be worse. She says the daytime is what counts and it is not a concern in the day.

She got her first job with the March of Dimes after her accident and she was nervous on the car ride there which made her worried that she might have a bladder accident, but she made it. Her last day of work was three years ago and she was feeling sick that day. She was unable to get off the toilet on her own and it took three fire fighters to get her off. After that experience, she was worried that she might not be able to live on her own anymore. She got a commode but was afraid to go to the washroom because she might not be able to get off the toilet. She had her toilet elevated and says her landlord is phenomenal at doing those sorts of things to help her.

Her worst case scenario with UI happened last year when she was with people from work at a goodbye dinner and she suddenly had to go to the washroom but did not make it in time. She put a smile on her face and tried to finish the evening as quickly as possible. She came with a close friend and it was not a big deal to her, so she put the cushion from her wheelchair on the car seat to keep it clean. This ruined her whole night, and it was not pleasurable or fun. She says that this does not happen often, and the

experience would not have been so traumatic if she was with friends as opposed to work colleagues. This did also happen on a plane and she is now afraid to fly for more than two hours at a time because she might not be able to hold her bladder for any longer than that, but she says she can hold it all morning when she is at home because she knows the bathroom is right there. When she goes out, she is always afraid that she will see a toilet that is too close to the ground and that she will have to call for help to get off the toilet. As a result, it is important that she goes out with people she is comfortable with.

She describes her urologic management program as ‘meh,’ and says that it works for her in the daytime. She is not willing to take more medication to help with the incontinence she experiences during the night because she does not want to change the way her bladder operates during the day. She is not ready to be catheterized yet, though she assumes it will happen when she gets older. Being catheterized is her biggest concern and she does not want “more things to carry” with her. As a precaution, she wears the most absorbent pads. She also buys disposable pads that go on the bed when she travels away from the home. The bed pads that are available in Canada are poor quality and the cost of shipping the higher quality pads from the United States is quite expensive. Watching what she drinks is another way to lessen the occurrence of UI. The things that bother her most about UI are not knowing when it will happen, and the clean-up that is involved. It is a pain [nuisance] and a lot of work because she does not like to be dirty, so for her it is not just a quick wipe up, it is a whole shower. She finds that bladder infections increase the chance of UI, and when she has one, she cannot get away from the toilet. They do not happen often and she always has medication on hand in the event that she does get an infection.

The amount of disclosure she would give to a potential new sexual partner regarding UI would depend on the person and the connection between them. She would have to be comfortable with the person before telling him anything because nothing sexual would happen until that point. She would tell the guy about sex and UI when they were becoming more intimate unless they clicked right away and she felt a connection. If she did not feel a bond, she would “not be so generous with her affects.” She would rather have things out in the open, but says the ground work has to be there first. Putting it on the table is half the battle because it would get her “nerves out of (her).” In her opinion, open and honest communication regarding sex is important if there is love, respect and friendship. If there is a problem and you have those things you can work through it. If not, communication is immaterial.

She knows the statistics about sex after SCI, but does not agree with them. She says you can do without sex and it does not help you survive, but you cannot do without bladder and bowels so those should be more important. A man with SCI who she did not know came to visit her and said “more important than sex and even walking is bladder control” and she agrees with that. She does not put sex at the top of the list, but says that bladder is at the top of her list.

When she listens to people complain about things, she thinks that they do not realize how lucky they are and that they should appreciate things more. She is appreciative because she could have been completely paralyzed or could have even died. She says she is lucky that she can live independently because she loves her home, and she loves being independent.

2. Caroline

P2 is a sexual person and sex has always been a big part of her life. She says that sex is important in a relationship to stay close and connected with your partner. Her mom was open about sexuality and talked about it bluntly which has made her able to talk about sex with people without being shy. Before the accident she had a couple of long term relationships in her teens and was sexually active since the age of 15. She had a few partners before her accident, and always enjoyed sex without any type of sexual difficulty. She was a little bit wild after her accident and had a few more partners while trying to prove that she could still attract men, but she was uncomfortable and worried about “bathroom things” (bladder, bowel, gas) going wrong during sex. She was always paranoid of those things and would find it totally embarrassing if they happened, especially if the person did not understand. She calls those initial sexual experiences “conservative sex with no exploring.” She was so afraid she would “shit on someone’s face,” and that was her biggest fear. When she met her husband, she realized that being comfortable with her partner was necessary because she had to be more creative after SCI and had to trust that he would not get scared of these things and run away. She says that her husband knew about them from day one, and as he learned nothing scared him. The SCI has forced P2 to do more exploring about how to be sexually satisfied. Her sex life is still great, but her sensation and the ability to be spontaneous have changed. After being with her husband for 10 years they are still happy and have a lot of sex which is a very important part of their relationship. Her sexual activities have not changed since the injury. Her and her husband have tried pretty much everything and have explored what feels good. She says they have been ambitious that way. Her and her husband are very open and willing to try things sexually and she does not think that he has any concerns.

When she was in the hospital and was told that she could still have sex and that it could still be good, her reaction was happiness. Sex was important in her life before the injury, and she hoped it would remain that way after so it gave her a sense of relief though she still had a million questions. She was in the intensive care unit with a trach and was hooked up to life support when she asked about sex. She asked about it right away and sex was one of the first issues that she was thinking about early on. The nurse told her that sex was not important and that she should be focusing on other things which made her frustrated because the nurse did not know her, so how would she know what was important to her? She did not ask about sex for a long time after that.

At the time of her accident she was a “party girl,” but she did see herself as a married person with children one day. Her parents had been married for 35 years at the time and she wanted that too, she just did not know when. Her injury made her want to get married even more because she wanted to be with someone who did not care about all her “stuff.” She would not have to explain bladder and bowel anymore because they would no longer be an issue, and she just wanted someone to love her forever. She was injured at 18 and married by 21.

She was in a casual relationship at the time of her accident, and thinks the relationship ended because she farted in front of him and he “freaked out.” She was just out of the hospital, but still in rehabilitation and on medication, and she remembers a horrible sound coming from her body. She was horrified that he was there, and he disappeared after that. She says there were probably other things, and he was afraid of everything that went along with the fart. Her mom is very supportive and said “if he can’t handle the farts, how is he going to handle the poo?”

The body issues that concern her are bladder and bowel related. She is always a little bit worried about them, and they are always at the back of her mind. She has experienced a lot of UI since the accident, especially when she was pregnant and she had UI daily from 6 months on because of the “giant baby sitting on her bladder.” She says even able bodied women pee themselves during pregnancy. Urinary incontinence is rare for her now and is not really a concern because of the Ditropan, but it was constant for the first year during which time she wore pads but would sometimes leak through. She was taking Detrol which she says was not very effective, and as soon as she started taking Ditropan the UI stopped instantly. Urinary incontinence happens very rarely now, one a month or every other month, and mostly if she is leaning over and squishing her bladder. Her urologic management program is quick and effective and she has tweaked it so it works for her, but it took her a long time to figure it out. She had one nurse who she thanks very much because she made sure that she learned to pee on the toilet which gave her a lot of freedom to go in places that are not accessible. It took her a lot of catheters and a long time to learn, but now she can pee as quickly as any of her friends.

She was always afraid she would “pee or poo” during sex at the beginning, and has experienced bladder incontinence during sex. She was frustrated when she was doing everything right but still having a lot of UI. The first time she had UI during sex, she told her husband it was a g-spot orgasm because she did not want him to know what it really was. Thankfully she was at home so she could wash the sheets. She says being incontinent during sex has been embarrassing, but her husband never made her feel stupid about it, so she was able to get over it. Urinary incontinence does not affect her sexuality anymore because her husband has seen it all, but UI is still a little bit scary.

She gets frustrated sexually because she cannot feel things the way she used to, and because it took her so long to have an orgasm. When she was having UI, she did not want to do things sexually that were “outside the box” that might trigger UI such as oral sex, being on top, and changing positions. She says those things were scary and that she has been afraid to do certain things that felt good because she feared they would trigger UI. That stopped her from enjoying sex as much as she should. Her fear made her more conservative about positions instead of just doing what felt good. Precautions to prevent UI affect the spontaneity of sex because she has to go to the washroom to catheterize and make sure that her bladder is empty before having sex. This affects the mood by stopping the momentum and putting a damper on things which is a bigger issue for her than for her husband. He is fine if she has to stop to go to the washroom because he is used to it. Sometimes she will catheterize before she initiates anything or if she thinks the opportunity for sex might present itself so they do not have to stop. If they are in the middle of sex, she will not stop as long as she knows she will not be incontinent and just hopes that everything else will take care of itself. She has not had a lot of bladder accidents because she is proactive about it. She takes Ditropan, but takes it as infrequently as possible because of the side effects. She is supposed to take it three times a day, but takes it only once which is just enough to be effective without creating such overwhelming side effects that she can no longer function properly. She says “you have to find a balance so it works.” She has tried other medications but they did not work. She wears a pad and catheterizes a lot even if she has just the slightest sensation she has to go because she cannot risk it. She experiences more UI if she has a bladder infection and becomes more concerned that she might pee on her husband or wet the bed. She is afraid

that if she is receiving oral sex she will have a bladder spasm and pee in his face, which she says “isn’t hot.” Having pressure on the bladder, drinking beer and menstrual cramping increase her urge to go to the washroom, and if she did not get there in time, it could lead to UI.

Her worst case scenario with UI would be in a professional setting. Being soaked through during a presentation and having to sit in it in front of colleagues or clients would be more embarrassing than if it happened with family or friends because she is more comfortable with her family and friends and they do not care anymore because they are so used to it. She once soaked a guy while they were fooling around and she will never forget it. She does not think she ever saw him again and she says that “you scare away all the guys that can’t handle it.” If she was not married, that type of thing might be the worst case scenario with UI, but as a married person “the professional thing is worse.” It is scary because professionally she wants to be respected and she might lose that respect if she becomes “Mrs. Pee-Pee Pants” because people might not understand.

She was funny about not telling anyone anything about UI and would give zero disclosure to a new partner. Now that she looks back on it, she thinks that she probably should have told them, but she wanted them to think of her as a sexual person. She did not want the thing on the guy’s mind to be worry, wondering if she was going to pee on him. She might be worrying about it, but did not want him worrying about it. She did not want to explain anything at first, but says that you should explain things after awhile. The appropriate timing would be once you are in a serious and comfortable relationship. She was “not about to share a very private thing with a new guy” that she was “just hooking up with for the first time.” She would not necessarily tell him before being intimate, just

when she was comfortable. She says it sounds strange that she would be intimate with someone before she was comfortable with them, but says there is a difference between having sex with someone and being in a long term relationship. Her husband is smart and has a cousin with a disability so he figured out a lot on his own, but she did have to explain some things to him and it was over a year before he knew what was going on and how everything worked. She thinks that open and honest communication is very important, especially after SCI because there are so many more things to worry about especially with sex. She is very blunt with her husband and tells him everything that is going on, even to a fault.

The thing that bothers her most about UI is the “pain in the butt” [nuisance] that it is to change her clothes, change her chair cushion and to get cleaned up. It is an inconvenience more than it is embarrassing because if she is sitting in the chair she can hide it until she transfers, but it is always a pain [nuisance] to clean up.

3. Brooke

P3 has always been comfortable with her sexuality. She had been sexually active throughout her teens without any sort of sexual difficulty and had a boyfriend of four years at the time of her injury who her family did not like. He lived in the United States and travelled a lot for work so she did not see him very often. She was visiting him in Florida when she had her accident on his dirt bike and which made him feel guilty about her injury. Her parents put a lot of blame on him for the accident and she was unable to mediate between them because she was in a comma at the time. They had talked about spending the rest of their lives together but a lot of things were said during that time that could not be taken back and she is not even aware of what they were. He did the best he

could, but she says that he could not handle it because he felt responsible for what had happened. He became depressed and ended up in rehabilitation for drug use. They did not want to break up but had to under the circumstances, and P3 thinks that if she had not been injured, they would still be together. She says that she took out a lot of her anger, sadness and frustration on the people closest to her including her family and her boyfriend which she still feels bad for. She says her family stuck it out, but her boyfriend was not strong enough because everyone was against him. He wanted to protect her but she says that she felt like he was no longer attracted to her and that neither of them knew how to handle her body. Their intimate relationship disappeared, then their overall relationship. She knew her family and friends loved her, but she needed intimate physical attention above that which was and still is difficult for her.

The first thing she wanted to know after her injury was if she could walk, followed by if she could have sex. She wondered if she could have sex, feel sex and enjoy sex. She wondered if she could have an orgasm, and if she could have children. She is still scared that sex will not ever be the same or feel the same. She got some information from a peer mentor in rehabilitation which helped her begin experimenting as soon as possible because she had confirmation she could climax. She did not know if it would be the same as her mentor, or if it would be the same as it was before, but she wanted to find out. She wanted to experiment sexually soon after the injury to get answers to her questions because it was important to her, but her boyfriend said no because he thought she was too fragile and he did not want to hurt her. She would have been comfortable experimenting sexually with him because of their history together. She was offended and thought that he must not find her attractive anymore. She worried

because she thought that he could be with any other girl, so why would he stay with someone in a chair who is a defect, or defective? She had a lot of time when she was in rehabilitation and her mind wandered, thinking about if her boyfriend would come back to her, if she would have a boyfriend, if she would get married, etc. The one nurse who talked to her about sexuality suggested that she experiment with a vibrator, but the vibrations made her feel sick and she was unable get turned on by herself. Even though she was nervous, she was willing to be with new guys at that point because sex was something that she wanted and needed to be fulfilled. She says you learn with time what you like sexually and that sexual activities have changed in a huge way since the injury. She used to enjoy romantic sex, but now that she lacks feeling she likes it more rough with slapping and hair pulling which she would not have liked before but now loves because she can actually feel it. Guys do not want to hurt her but she directs them as to what to do and sometimes they are afraid. She worries about where her legs are during sex because even if she cannot feel it, she can still pull a muscle. She used to like showing her body off and was not afraid to get down to her underwear, but that has changed since the accident. She always wore a brief and that made her feel like a baby or like a grandma. She was terrified that the guy would notice it because of the noise they made or if he touched her butt which she would not even feel.

She sees guys check her out, but she is not sure if they are looking at her, or the chair. She thinks they see the chair first and that they are curious why a pretty girl is in a chair. Unfortunately, a lot of times the guys' second question is if she can feel sex. She says that is a turn off but because she does not get attention like she used to, she never walks away from it, even if the guys are not the greatest. They may seem like jerks, but

after they learn what she has gone through they respect her a lot more. She did not think she would ever be with another guy because no one would be interested in her and she is not satisfied with how difficult it can be to find someone willing to be with her. She says it was easy to find someone willing to make a relationship work before, but it is hard to find someone willing to make it work with someone in a chair. She has been in an out of relationships that have been a lot harder since her injury which is different than her long term relationship leading up to the injury. She says that guys have taken advantage of her because they thought that no one else would want her and that no one was going to sweep her off her feet and take her away. Guys could control her since they always knew where she was since she was not driving yet or having a life of her own, and would not give her straight answers about their whereabouts.

Due to the high spasticity and low volume in her bladder, UI is always a concern. She goes to the washroom more than normal because her bladder cannot hold a lot, and she gets autonomic dysreflexia (AD) symptoms so she can sense when she needs to go which is a blessing. She takes the top level of Ditropan which is not covered by any plan, and she has recently had bladder Botox. Since the Botox, she can go longer between bathroom breaks and experiences fewer AD symptoms. She still goes to the washroom before sex out of habit to avoid UI. When she was on Ditropan, she was 75-85% sure she would not be incontinent, but she was still concerned about it. She feels 100% better with Ditropan combined with Botox. She is very satisfied with her urologic management program since the Botox and says it is the best it has been in three years, but her bladder is not the same as it was before the accident, and there will always be that comparison. She used to be worried about accidentally voiding if she did not get to a bathroom, but she

can now hold it. She used to wear a brief, but now since the Botox she is not concerned, nervous or aware of her bladder and can sleep through the night in just underwear.

Wearing regular underwear makes her more comfortable around guys. She says that even if it is granny panties that she is wearing, it is still real underwear and that helped her confidence and self esteem greatly. She has had a lot of frustration with herself regarding UI. She has accidentally wet herself on a date and was so angry that she had to deal with this while changing in the bathroom stall. Her biggest concern and fear about UI is being rejected, and that the guy would not want to do anything with her because of it.

Because guys are either thinking, or going to be thinking about sexual function, she tells them right away and she covers the topics of toileting, catheterizing and how her body works. How much and when she tells them depends on their intentions. It would be sooner if it was just sex, and later if it was a more serious relationship, but it would be before being intimate. She would tell them as much as they wanted to know, and would keep “spilling the beans” right from the beginning as long as the guy wanted to learn. They usually do not care because they like her personality by this point. She is more open to explain it because she has never had someone respond by saying “eww, gross” and she tells them UI happens to lots of people, not just people in chairs with SCI. Women who have had babies and whose bodies have changed may experience UI, but guys still consider them “MILFS.”

Urinary incontinence before the Botox affected her sexuality in terms of who she would have sex with and when she would have sex. She wanted to be comfortable with the person before telling him about the possibility of UI even though she would still be embarrassed and worry about being able to face him the next day. After a few dates she

has to explain bladder issues, among other things, which is terrifying for her, but surprisingly guys are generally interested and understanding. She uses her 'mat' and some guys get what it is for, but most do not care in the moment. Right before sex, she may bring up the possibility of UI by warning him that she might accidentally void a little bit, but it depends on how much she likes the guy and how comfortable he is with her. Having that conversation "just sucked," but she knew she had to tell them out of respect, and also to get what she wanted (sex). She would want to know if the situation was reversed, and she says that she would be understanding but she knows that not everyone is as understanding. Sometimes she says nothing and just hopes that it will be fine. Most times, sex happens at the guy's home so UI is more embarrassing because it is in his bed and on his sheets. In this instance, she will offer to clean his sheets. Most guys do not even notice until after they have finished, and sometimes they cannot figure out what the wetness is. They sometimes ask if it is sweat and she will say that it is so they think it is something other than urine.

Her worst case scenario with UI that actually did happen was when she accidentally had UI on her partner's bed that he had just bought and was very proud of. She freaked out and apologized, and they stripped the bed as quickly as they could. The guy said it was okay because the mattress was okay. She wanted to leave.

She goes to the washroom before sex, and if she is making out with a guy, she will stop to go to the washroom to make sure UI does not happen during sex. Emptying her bladder is the main thing she does to avoid UI, however, when her bladder is empty she does not feel as much sexually. If she does not empty her bladder she is unable to enjoy sex because her AD symptoms are too distracting. She carries a blanket in her bag

of supplies that she lays down and takes away with her if UI happens. Guys comment on her level of preparedness and she tells them that things work differently for her. She does not eat too much before sex and makes sure she has had a good bowel movement because it would be a lot of pressure on her bladder which would worry her. She has more incontinence if she has been drinking liquor or if she has a bladder infection which is the main thing. She never had bladder infections before the accident but has them all the time now. She worries about leaking during sex if she has an infection because the urine would be darker, cloudy and would have an odour. She has leaked during sex when she had an infection, but neither she nor the guy brought up the odour so she did not care but, she says that it has the potential to be really embarrassing.

Guys are concerned that they will not be able to satisfy her sexually. They worry about the unknown, and they do not know what to expect or how to handle it. She tries to make it as easy as possible by explaining things which she finds herself doing a lot and wishes she that she did not have to. Even if a guy is not pleasing her, she will make it seem like he is to be a nice person. She also worries about her ability to please her partner and that she might come across as selfish which she has just become aware of since the injury, possibly because she was always in a long term relationship before where her and her partner knew how to satisfy each other.

She never thought of some of these things before. She says that she is the same person, but not the same. The memories she reverts to now are usually those from before the accident and that is where she reflects more than ever. Despite all she has conquered, UI is still always on her mind, and she will always compare herself to 'before.' No matter how old she is, she will always be comparing herself to when she was 21 which is

difficult because of natural changes that occur with aging. Before the injury her only concern was if a guy was clean and sexually transmitted disease free, but now she has so many more things to think about. It has caused a lot of bad emotions and it is a drastic change that she wishes she did not have to worry about because she did not have to before. She says it used to be so much easier and that she will always compare to what it was like before, and what she took for granted. She says she cannot make people understand what they take for granted, and even her sister who sees her everyday only kind of gets how lucky she is. There are certain places she that she cannot go and there are always washroom issues, but people are usually accommodating. Her friends will invite her places but they do not think ahead of time like she does. She wishes she could still be playful, but she has worries on her mind she that she did not have before, and that gets in the way of all sorts of relationships.

4. Clay

For P4, sexuality is comprised of intimacy, passion, movement, positions, playfulness and places. It is something you do with someone who is more meaningful than the average person. Heterosexuality is what she chooses, but she is open to other types of sexuality. Before the injury, she had a very active sex life and considered herself to be a very sexual person without any type of sexual difficulty. She would have sex anywhere and in all kinds of positions. She thought she had nice legs, a tight butt and moves on the dance floor, and she was quite successful at attracting the opposite sex. Her criteria for a man was hot, muscular and looks good naked. However, now when she looks in the mirror she does not see all the qualities she would use to define what 'sexually attractive' means, and her sexuality has changed because she feels she is

missing some of the key components of sexuality including attractiveness, sexual confidence and feeling desirable. After the accident she thought she would never have sex again, and that no one would ever love her, but those feelings evolved over time. When men started picking her up, she realized she was still in the game, and she is 15 years post-injury and has had a whole lot of sex. Before the accident it was culture, society and her parents that contributed to forming her attitude toward sexuality, now her attitudes are purely based on her experiences.

P4 is engaged, but when she met her fiancé she told him that she did not think she could do forever, so give her 10 years and she would think about it. Ten years later he remembered and she says he is a beautiful person and the one she wants to spend her life with. She likes to think the SCI did not play a factor in changing her mind to get married, but she has caught herself thinking that she better scoop this guy up because he may be the one and only person who accepts her the way she is. She did not base her decision on that, but she did think that she better seal the deal. She does not know what her partner's concerns are about their sexual relationship because he has never expressed them. She thinks that he might be concerned about hurting her, but says that that is not different from her own concerns.

Sex since the accident is awkward and difficult, but not as much so as she had imagined. It is very different now in the way she undresses, the foreplay, being 'ready' and lubricated and the positions she has sex in. She likes making things look easy even when they are not, and she has struggled with that. She wonders how a mostly paralyzed person undresses in a sexy way. Before the injury, foreplay could have been anything; dancing, undressing, role playing etc and now it is more calculated and involves getting

ready to have sex; being undressed and lubricated. She will pee, then they play, then she will pee again, so there were two pees before the actual penetration part. She says it is a lot less playful and more about the task at hand. It is more about how it comes together than the romance of it all which affects the experience and she worries about the person she is doing it with wanting to do it again. She has been doing it this way for so long that she says she is used to it and it does not really affect her anymore. In the beginning it had more of an effect so she eliminated foreplay because so many things could have gone wrong or been noticed. It was better to get on with it quickly before bladder accidents happened, and to mask the body and move it away from being about the body as much as possible. She says she is lucky in terms of lubrication because it tends to be responsive and appropriate, but it is a little harder since her second accident. She says she has been frustrated when her mind is ready and she wants to get laid, but her body is not ready. She was told she could go autonomic and she did a few times, but she experienced AD so frequently that she did not let the fear the Doctors tried to evoke in her about it causing heart attack or stroke get to her. She figured she could have AD if she bent over too long, so she was not going to avoid sex because it could cause her to become autonomic.

She liked to be naked for a long time before sex to work up the desire. She used to like the 'to be looked at' part of sex, but does not like being looked at anymore. She is less comfortable naked not just because of what she looks like, but because of the practice of undressing and how she moves. Positions are different now because of changes to mobility. Her body does not 'hold,' and there is no standing or bending because it is uncomfortable. She has been at different phases in her disability because she has had two separate SCI's. When she could get to her hands and knees it was great

because from there she could get on top. It was a lot of work but it was fun because it is her favourite position. She says that it is sexy and that she likes to be in control; going at her pace and depth. It also makes her body feel more useful, like her legs “aren’t just good for nothing” because they are weight bearing and it is a position that an able-bodied person would do which makes her feel more normal. It was okay to be on the bottom before because she could be on the top, but now the bottom does not feel as good because it is the only position she has got versus the one that she chooses, and she is the adventurous type so it is not okay for her to just lay on the bottom. She is now back in a place of limited mobility so available positions are from the side, back or with her on the bottom which can be quite painful. Her biggest challenge that keeps her from enjoying sex now is the pain she has.

Her SCI has affected her self-confidence and sexual-confidence in a number of ways. She has been apprehensive to take certain paths of travel which affected her integration and the possibility of meeting people. Also, if she saw something she wanted, she was the type to go after it and be the initiator, but after her accident she did not have the confidence or self-worth to seek what she wanted. It would have been nothing for her to approach a hot guy, but she would no longer do that after the injury. Instead, she waited for people to come to her which she says was effective because the men who approached her were more emotionally mature, in touch with others, compassionate and nurturing. It was a safety net because she was not going after a guy who would not be caught dead with someone in a chair. Initially, she thought the guys approaching her must have already tried everyone else and must be really desperate, but if she did a study she

thinks she would find that it takes compassionate and empathetic men to be with someone who has a disability.

Sexual-confidence was non-existent and was more experimental. It took her a long time to try different positions and only when she was really comfortable with someone she might then suggest that they try something new, but it was not in the heat of the moment, passionate way it had been before. Also, having the same partner helped her to be more experimental. It started with her just being on the bottom, but she surprised herself with what she would do, and has blown her mind with what she has been capable of. For example, she had sex in a car while the guy was driving and was able to transfer from the passenger seat and get turned around. She says it was dangerous but fun. It took a good two years to re-develop sexual confidence, and the things that contributed were experiences and doing things she did not think she could.

P4 is very satisfied with her urologic program and says that her bladder has come a long way. She experiences UI once a week which she calls “rarely,” but it is a concern for her because it is always in the back of her mind. She takes Ditropan which she says might affect her ability to become lubricated, but she does not take anything that would directly affect UI or sexuality. After all these years she has a pretty good handle on it and knows when she needs to pee and how much she can drink, but it took her a long time to get to this point (10 years). The second SCI helped the UI and was almost a gift because it affected the sacral spine and relaxed her bladder so it was less hyperactive. Without the second injury, she does not think she would have reached this level of satisfaction and that she would have been looking for a surgical intervention. Before the second injury, no matter how much she catheterized her bladder just liked to spasm, and during that time,

she was guaranteed to pee during sex even if she has just gone to the washroom. She thought she would be single forever, that no one would love her, and so much for a sex life. She says “it forces you to really get to know someone before being intimate.” Before the injury she would date someone for a month before sleeping with them, but after it was five or six months because there was a lot of information to share to get them prepared and to make sure they were “still game” given everything. During that time her bladder made her feel “not sexual.” She felt scary, gross, undesirable and ashamed. She gave UI so much power that she could have great sex, but if it ended in UI, it would take away the good and become a horrible experience. Usually her partner would be the one to comfort her. Because of the UI she refrained from sexual activities for a while and says that she probably would have had sex a lot sooner after SCI if UI was not an issue. It stopped her from having sex when the moment was otherwise right, and delayed her from having sex altogether. Her personality type allowed her to experiment sexually, and she tried to think that “for as many times that there were issues, there were times when there were not” and that helped her to keep going and stopped her from becoming ‘asexual.’ She says the stories we tell ourselves are key in deciding if we will grow, or shut down and give up.

The worst thing about UI was at the point in her injury when she had lost sensation, so she was peeing but was unaware that she was peeing. Not only was she peeing, but she was clueless that it was happening. She says it is disturbing not to be the first one to know that your bladder is working and to have someone tell you that you are peeing. She says it is frustrating when her bladder or bowels are supposed to work and they do not, or worse, if they do work when they are not supposed to.

Her worst case scenario with UI and the thing that would be the hardest to get over would begin with infection; so stinky, smelly, cloudy and sediment filled urine, and then having UI while someone is giving you oral sex. She says as bad as it would be for her, it would be 10 times worse for the guy. She says that it is one thing to be peed on during sex (which she does not think is that bad, probably because she has done it so many times), but that it would be traumatic to pee in someone's face. She says just a fear that it could happen, and not even that it actually did happen, made her heart race and made it so that she could not enjoy or feel good about sex. It went from being something enjoyable, de-stressing, relaxing and euphoric to something that could cause anxiety or a panic attack which is the opposite of how she thinks sex should be. She was sweating and not because it felt good, it was because she was not feeling good. This fear did not prevent her from receiving oral sex because even though she did not have control of her bladder, she knew when she was peeing because it was during the time when she had sensation. She now has a record of mostly successful sexual experiences without UI so that dictates how she feels, but there was a time when UI was her greatest fear.

She once planned a threesome for her and her boyfriend to be with her friend's younger sister who she says was way more attractive than her which was a bad idea. They began foreplay and then she had to leave to go pee. When she came back, her boyfriend and her friend's sister were already going at it. She was mortified and angry and got rid of the guy right then. She thinks that if she did not have to leave to go pee it could have been a very different experience. She had never had a threesome before that day, and after that experience, she would never try it again. Her bladder had such a huge impact on that situation.

She says that her sensation is very muted so it is sometimes difficult to distinguish between stimuli. She once peed at the same time she had an orgasm and she was unsure if it was the peeing that had caused it. The next few times she had sex she would sneak her hand down when it started feeling really good to see if she was peeing. That took away from the pleasure of being in the heat of the moment and made her panic, wondering what it really is. At that time she thought there was a connection between UI and orgasm, but it was short lived and she identified she did not need to make that connection because when it was feeling good, she was not peeing. She says it is really sad when you are having sex and it is fear and worry that you feel. She says if it happens too often you withdraw and do not want to have sex because it stresses you out instead of making you feel good and euphoric. It also had a lot to do with her partner's reaction. If he was understanding it would be better than if his response was "oh god!" She says we are our own master and having someone say that it is okay is comforting, but it does not really make it okay.

The appropriate timing to share information about the possibility of UI during sex would be based on intuition, not time, and it is not a science. It has to do with the relationship and how open the person is. She would share the information using humor and jokes and then follow up by saying "it wasn't really a joke," and she would tell them slowly, bit by bit. Having the conversations sucked, and made her feel nauseous and nervous, but it had to happen for the relationship to evolve. She says it is human nature to be inquisitive so if she said something, it would usually prompt the guy to ask questions and that would determine what she shared. She left information about AD out of the equation because it is scary, and it is quite involved to teach someone about the nervous

system. Only if AD actually happened would she would explain what was going on, and she would pretend that everything was okay until it was not okay. The response was typically panic, worry and concern. From that point on, the guy would always ask if what he was doing was going to cause AD, and that took away from the moment.

Having those conversations was very awkward. Her heart would race and she was nervous because she did not know how the guy was going to react. She thought it was a huge risk to tell him, but a necessary one because he may be uncomfortable and not want to go any further, or even worse, he may think that he is okay with it and then in the moment when it actually happens, he could find out he was wrong about being able to tolerate it which would be worse and make her feel even more shameful. It would ruin the relationship because she would then be mad that he reacted that way after she tried to work it out, and he is disgusted. She did have that experience and the relationship ended abruptly. She never really dealt with it, she just pushed it down, buried it and moved on. She says that it is a necessary conversation to avoid those situations unless you can take the hurt, pain and anguish that comes with being rejected. She would rather make the effort to avoid feeling that way. She says it is one thing to have the conversation face to face, and another to do it “butt naked.” She says it is easier to take the rejection when you are fully clothed and in a different setting.

Drinking is the only thing that increases her UI. Before the second injury SCI, precautions she would take prior to engaging in sex would be to lay down a “pee pad” as part of the “getting ready” part so she would not pee on the bed if she was incontinent. It took away from the passion, the romance and the heat of the moment when she would have to say ‘let me put the pee pad down.’ She would also go pee before sex, though she

wondered why because she would be incontinent anyway, and when she would leave to go pee they would have to start all over. She used to wear pads and diapers but would take them off long before even laying next to a guy so he would not catch on. She says that she tried to keep secrets.

She feels segregated and says that for the first time in her life, she knows what the Black people felt like because she is not allowed in certain washrooms because they were not accessible to her. She thinks this is “sick and twisted,” and says that though there have been improvements, 75% of the space on the planet is not accessible to her and there is still a long way to go. She says “you hope to learn to catheterize on a toilet because that really changes things.” She says that it is one thing to go to the washroom to pee and another to ask the guy to please leave while you pee on the bed and then dump it in the toilet. If she was going to date a guy, she wanted to at least be normal enough to pee on the toilet like everyone else. She was set up with a leg bag but thinks that she probably never would have gotten into bed with a guy with a bag of urine attached to her leg.

5. Sarah

Being a sexual person holds a lot of meaning for P5, and it involves having a relationship and being intimate. She does not describe herself as a “love-dovey” person, so her intimacy, touch, and her way of saying ‘I love you,’ comes in the form of sex. She describes her ex-boyfriend as “that scary boyfriend every girl has in her past.” He cheated on her and was abusive, but she let it happen because he was manipulative and she lacked life experience. She also had a poor relationship with her parents, so her ex-boyfriend became her “only person in the world,” and she stayed with him for six years, two of

which were after the accident. Her ex-boyfriend would do all sorts of “love-dovey” things to make up for the cheating, and would constantly make P5 tell him that she loved him. Her and her current boyfriend refrain from such acts unless it is during sex, and they do not feel the need to prove their love. Because of her difficult relationship with her ex-boyfriend, she appreciates her current partner very much, but sex has become more complicated for her. Her ex-boyfriend would tell her that he was just having sex with the other women, but that he ‘made love’ to her, so her current boyfriend will not just have sex with her as to not hurt her feelings, even though sometimes she just wants a “wham bam, thank you m’am” and move on. She has been with her current boyfriend for approximately seven years, and even though they are not married, they feel like they are. They have a daughter together and know from experience that they do not want her to grow up in a broken home.

She was a very sexual person before the injury because her ex-boyfriend required her to be that way, not because she wanted to. Now with her current boyfriend, she enjoys being a very sexual person. She has varied her sexual repertoire since being with him because it is at her discretion with someone who listens to her, and because there are more issues to work around as a result of the SCI. She did not have any sexual difficulties before the injury, and lubrication would happen “on command,” but this is no longer the case. She did not use toys or touch herself before the injury because her ex-boyfriend told her that “good girls” do not do those things, and because her mom would walk around naked and leave sexual toys around the house and she did not want to be anything like her mother. Her current boyfriend is very experienced sexually, and she says that it took him a long time to get her to come “out of her shell.” She has gotten vibrators and other

toys in her Christmas stocking which they use on each other, and he tells her to “have her way with herself” which she has tried, but she prefers his touch and the way he does it. She is not sure if she would be this open sexually if it were not for the SCI. It is now more difficult to be sexually satisfied than it was before the injury, and that has led her to try new things, but she thinks it also has to do with the person she is with allowing her to explore and change sexually.

Sexual desire and sexuality in her relationship in general have decreased since the accident. Before the accident, she would have sex “anyplace, anywhere, anytime,” but now she cannot just “duck into a bathroom” or stand in a shower to have sex. Sex only happens on the bed now because it works logistically. They have tried to have sex in various places and positions, but it is just “awkward.” She would like to be the aggressor, to be on top, take charge and just “sit on him and go” because it turns her on to be in control, but she cannot do this without his help, and she no longer has enough movement to be on top. She holds her legs during sex so that they do not spasm and she says “the least I can do it hold my own god damned legs.” For these reasons she is frustrated sexually, and she says that sex is less exciting now because it is almost the same every time. She says there is no “explosion” at the end and she spends a lot of time trying to make herself believe that she can feel things. She has some feeling which requires more stimulation than before the accident, and says that she does not have the “happy ending.” It could take her an hour or two to reach her climax, and sometimes she is just too tired to continue and would rather go to bed. In this case, she will sometimes fake an orgasm to make her partner happy because he always wants to please her and gets upset if he is unable to do so. She thinks his biggest concern with their sexual relationship is being able

to please her which he always tries to do, but does not always happen. She wants him to just enjoy sex, and says that an orgasm for her is a lot of work, and she is unsure if it is worth it. She remembers what sex and orgasm used to be like before the accident, and hopes to get that back some day. She is confident in her ability to make him happy “anytime of the day,” though she says that she cannot perform certain sexual acts as well because she does not have the same amount of muscle control in her hands that she used to.

Urinary incontinence takes up a lot of her life and affects her a lot. The medication she is currently on for the incontinence causes a number of adverse side effects that she says affect her sexuality by causing sleepiness and “stopping some sexual feeling.” She has tried to take herself off the medication, and to switch to medications with fewer side effects. She calls those times her “best weeks of feeling” and said that she felt “like a whole new person” but says that the other medications did not “hold” and because she cannot “pee herself 24/7” she had to go back on the pills that cause the negative side effects. Urinary incontinence also affects her sexuality as her boyfriend does not want to initiate sex because he thinks that she will probably have to void. She tries to go to the washroom before they have sex, but she believes that she is able to feel more when her bladder is full so sometimes they have to stop in the middle so she can go. He also does not initiate sexual activities in the morning, especially oral sex, because he knows that she will need to use the washroom when she wakes up. Urinary incontinence did not stop her from participating in sexual activities because she has peed on her boyfriend among other things. He is not surprised when these things happen anymore, and he is aware that this is the situation if he wants to have sex. The first time she peed

on him was at a wedding when he was carrying her to the washroom and she did not make it. They had only been together for two months, and it is now a running joke between them, but that was not her worst case scenario with UI. Her worst case scenario with UI was the first time she peed on her boyfriend during sex. She said it sucked, she was so ashamed and so embarrassed because no one wants to pee on their partner and she wanted to crawl into a ball, hide and never see him again because she “felt like an idiot for peeing on him.” She says she feels like a little 2 year old half the time because she is unable to hold it or do anything about it. She does not think anyone should be peed on and that it is embarrassing for both her and her partner. Being peed on is not pleasurable and she does not want to pee on him whether he says it is okay or not, she does not want him to accept it. He makes her feel okay about it, but it bothers her because it is not okay.

She did not give her ex-boyfriend very much disclosure about UI because he was not accepting of it and just wanted it to go away, but right from the very beginning, her current boyfriend knew everything she was going through whether he wanted to hear it or not. She says there is no hiding her situation, and as soon as you see her home, you are able to put things together. Having those conversations with her boyfriend was a little bit awkward, but she says she could talk to him about anything, and that is why she wanted to be with him. He accepts her without judgement, and makes fun of her to make light of the situation.

Sometimes during sex she is not sure if she is experiencing an orgasm, or if she is peeing because they can feel the same for her. As a result, she is concerned about UI when the sex is feeling good, and she will stop during sex to check to see if she has voided. She says there is usually no wetness there even if it felt like she had peed, so she

tries to let go and enjoy the experience because she knows her boyfriend will okay with it even if she did void.

She does not have as much UI as she did at the beginning after her accident, but certain things will increase the likelihood that UI does occur. She has more UI when she has a bladder infection, so the fewer bladder infections she has, the better she can control her bladder and the more normal her bladder feels. It also has a lot to do with what she drinks. Caffeine, acidic juice and water go right through her, so she drinks more Gatorade or anything that is decaffeinated. Alcohol increases her UI so she drinks more shots and less mix, and she no longer drinks beer because even though beer is all she used to drink, she cannot hold her bladder for very long and experiences leakage on occasion. Sometimes her need to void comes instantly. She does not get a lot of AD, and when she does have minor symptoms, she has already peed a little bit by then.

Her urologic program is “doable, but it sucks.” There is no control of her bladder, and no stopping UI. There is no peeing on her own and has to use a “stupid” catheter all the time. She had to have a surgery to remove a piece of skin that had formed like a flap from catheterizing too much and nicking the inside. She does not choose or want to deal with everything that comes with being in a chair, but cannot move on. She has to deal with this life and she cannot do anything about it. She wears a leg bag if she is going out or doing harder activities, and she can go anywhere with the bag, but she worries about it bursting or overflowing. She is at home most of the time and can just go use the washroom if needed, but if she goes out she has to find a washroom and make sure she does not go too far from it. It bothers her that she always has to be aware of where the bathroom is, and which one she can use. It would not bother her as much if she could just

go on the toilet. She has learned to go to the washroom in her chair and in the car because there are not a lot of public washrooms that are accessible to her. She drinks less if she is going out unless she is wearing the bag, then she drinks whatever she wants which makes her feel normal, though she does have to watch that the bag does not overflow. She also will not drink a lot before bed so she does not have to go to the washroom during the night. If she does have to go, she will just pee in the bed now because it will wake the whole house if she gets up. She says her body has a mind of its own, and her legs spasm making the whole bed shake so she cannot just creep back into bed. Sometimes the spasms cause her to make an involuntary grunting noise, and her boyfriend calls her “the grunter” and says she sounds like a porpoise. Having to get settled back in ruins her sleep which she says sucks, and her boyfriend hates her for it. She will not wear a diaper. She has not spent too much time looking into different ways to handle UI over the past couple years, so she says there might be something new out there.

She thinks that open and honest communication with your sexual partner is very important with or without SCI because if you are unable to trust, talk to and explain things to each other, and work things out, then there is no point to continuing the relationship. Her concern is that her boyfriend might leave her one day for someone without so many issues, and who is able to do everything because she would be able-bodied. The thought has always been in her mind that he might leave her, and she wonders why he would want to put up with so much. She has to put up with it because it happened to her, but he could walk away. He says he will not leave her and she has to trust him, but she wonders when “he calls enough is enough,” or when she “calls it

enough is enough.” She does not believe that anyone deserves to be in this situation, or to be knocked down.

She is not sure if this statement is some sort of racism, but she says that she could not be with someone in a wheelchair. She already has her own issues to deal with and would choose not to be with someone who is dealing with the same issues because it would be too much. She would not leave her boyfriend if he got in an accident and ended up in a wheelchair, but she says that she would be really mad at him.

Everything “bothers her most about UI.” She had not thought about a lot of these issues before because she says there is not anything that she can change about them. She never thought of bladder, sex or any of these issues before the accident and says it was “easy-peasy” compared to now. She says that she just had “no idea.” For example, she was unaware there was a third hole “down there” until she was 18 when they showed her in a mirror when she was in rehabilitation. She thought “that you peed and had sex in the same hole” and says that she just never paid attention before. She never put two cents into worrying about these things before, but now she has to think about them every day. No one wakes up and wants to be living with a SCI, and you would not wish it upon anyone.

6. Jessica

During the interview, P6 disclosed that she felt awkward and embarrassed to talk about sexuality. P6 was raped when she was younger which has affected her attitude towards sexuality. As she got older she remembered more about the rape and had a

nervous breakdown when she remembered what had happened. After that, she did not care about sex because it was not important to her.

Before the injury, P6 enjoyed sex and participated in sexual activities once or twice a week, but she did not care for it all that much because other things were more important to her. Though sexuality was still part of her and her husband's relationship right up until the injury, it was not a big part of their relationship. Since the injury, sex is no longer a part of their relationship and she has not participated in any type of sexual activity since her injury. Sexuality is at the bottom of her list, and she is not sure that she even wants a sex life because of her SCI and the resulting UI. At this time, she has no interest in sex at all and she is not frustrated with their lack of sexual relationship. She could care less and it is the last thing on her mind.

Open and honest communication with her husband regarding sex is not at all important to P6 right now. She has not discussed sexuality with her husband since the injury, and she would not be comfortable having that conversation because she would feel like a failure for both not wanting to, and not being able to have sex. She says she cannot talk about sexuality yet because she still has too much anger about the injury, and has enough other things to concentrate on and she does not need the added frustration. The frustration would come from not wanting a sex life, and as a result, she does not think or talk about sex, and she says she has no feelings about it. She pushes it aside so it doesn't exist. She will take it one step at a time, starting at the top of this list which is on the opposite end of the spectrum from where sexuality resides. She says that she does not know what the future will bring, and that her sexual future will depend on how she is feeling. She thinks that her husband might be concerned about if they will ever have a

sexual life again, but that is just a guess and she does not know his concerns because they have not discussed them. She hopes they will eventually discuss sex and that things will go back to normal, but since her idea of 'normal' is to be without a SCI she does not think that will happen.

P6 has been experiencing UI since her accident, but had never leaked prior to her injury. Urinary incontinence affects her sexuality because when she thinks about participating in sexual activities, she is concerned about her bladder leaking which would be embarrassing for her, and she is sure that her bladder would definitely leak if she were to participate in sexual activities. Though the smell and wetness of UI bother her, embarrassment is her biggest concern regarding UI, and she wishes that they would have addressed ways to cope with the embarrassment of UI when she was in rehabilitation. She says that it would not occur to her to disclose information about the possibility of UI during sex to her husband, or to even have sex with her husband because of UI, and that UI is the main reason that she will not have sex.

P6 did experience her worst case scenario with UI which involved leaking from her bladder and being unable to stop it when she was away from her home. She was at Brock University and one of the students said something funny which made her laugh and "Niagara Falls." She was the only one who knew that she had leaked, but it made her feel so awful, ashamed and embarrassed, like she wanted to crawl in to a hole because she says that UI is not "normal." She just wanted to get home because she felt dirty. She now catheterizes ahead of time so she can joke and not worry.

The first thing that P6 asks about when she goes out is where the bathroom is, but she says that she never thought about the location of the bathroom before the injury, and her concerns about the washroom affect the places that she will go.

Her UI varies based on the day; what she has had to drink and if she laughs or sneezes. She is unaware of anything else that would increase UI, and has not been educated about anything that would affect UI. Her urologic program consists of doing kegials and seeing an incontinence nurse. She says that it is starting to work, but that there is definitely room for improvement. She wears diapers all the time which she finds to be embarrassing, and her only precaution to avoid UI during sex would be to catheterize beforehand. Her Doctors do not think that her bladder function will return, and she will have to catheterize indefinitely.

7. Tina

Her parents taught her the value of sex, and told her that it was a part of life and that it was important for men and women to enjoy it. For P7, being intimate and having sex is a very important part of a relationship and is necessary to keep the relationship going. Having sex allows her to be close to her husband, and without it, he would be just like any other person to her. She says that it is important that her and her husband continue to be intimate because they love each other. She was very scared after her accident that her husband was going to leave her while she was away in the hospital, and that he would leave her for someone else if she was unable to have sex because sex is very important to men and she felt that he still wanted her in that way. Her and her husband thought that he was no longer going to be able to touch her, so her husband told her to ask the Doctors about sex right away. Her very first question after her injury was

regarding sex because it was important to both her and her husband, and they were surprised and happy when they were told that they could still have sex.

She thinks that it is difficult for him to have sex with someone who has a disability, and that she cannot move so she just lays there and does very little, but she says that he helps her. She did not know what she was allowed to do sexually after the accident and the Doctors scared her by telling her to be careful because she could have AD. Though the Doctors told her what to do if she became autonomic, she was scared at the beginning and found it difficult to have sex because she was worried her husband would do something that would hurt her and she that she would not be able to control it because she lacks feeling. She tries to make her husband happy.

Her husband was her first and only sexual partner, and she did not have any sexual difficulties prior to her injury. She describes sex before the injury as “normal” and occurring every two to three days. Approximately a year and a half after the accident, their sex life had nearly returned to normal again except that her husband does most of the work, and P7 reports that they engage in sexual activities less frequently than they did before.

She has experienced urinary incontinence since the injury, and at the beginning, she had a lot of bladder incontinence problems which affected her sexuality. She told her husband about her bladder related issues right after the injury, and he is aware of everything bladder related. She worried that if she was accidentally incontinent during sex, her husband would no longer want to be intimate with her. She does not have very much concern about it now because she knows that if she goes to the washroom before sex, she will not have any issues with incontinence. She also has to use the washroom after sex to

prevent bladder infections which increases the frequency of leakage from her bladder, and she finds having to go to the washroom both before and after sex stressful. A technique she learned in rehabilitation that she uses to avoid infection by ensuring that her bladder is completely empty is to lean forward and presses on her bladder while urinating. She is not sure what her husband's concerns are regarding their sex life together, and P7 states that it is not the same as before because she does not have muscle, but describes their current sex life as "okay". She says that life is not perfect, but you do what you have to do and her husband is okay with what they have now. She says that maybe later he will not be okay with their intimate relationship, but she really has no idea what he is thinking.

P7 has feeling in her bladder, but no control over it. She used a catheter for a year after her accident, but since she can feel when her bladder is empty and when she needs to go to the bathroom, so she no longer uses a catheter. She asked for a catheter in rehabilitation but they told her to get up and use the washroom because she had feeling. It was hard to transfer because of the lack of muscle in her back so they had to help her. She says the catheter was not easy to use, and her husband had learned how to do it and then he taught other people how. Sometimes she wants to use catheter now, but her husband does not want her to. She thinks that is because if he sees the catheter, he might think it was unattractive and it might stop him from wanting to be intimate with her, but she is not sure what he thinks. She says the catheter "damaged her life." She also says that her bladder does not work like a normal person's bladder, and that her bladder is the biggest problem that she has right now, especially when she has to be away from her home. That being said, she says that her bladder could be worse, so she is happy with her current

urologic management program, but she hopes it gets better. To this day, she compares her bladder and sexual function to before the injury. She says that it is a huge change that has affected her very badly, but she knows that her life is not over so she tries to live with what she has now.

She is not aware of any connection between pleasurable sexual sensations and urinary incontinence, but says that when she gets angry she experiences more incontinence, and as a result, she is scared to get mad. She also says that if she thinks about incontinence too much, her brain will send signals there and it will happen so she tries not to think about it, or worry about it. She says she is comfortable when she is in her home, but after four or five hours, her bladder gets too full and starts to leak. The worst time for that to happen would be when she was away from her home. She wears a pad when she goes out so she does not have to worry about making it to the bathroom in time, and if she does leak, she will be okay until she returns home. Her wheelchair and her commode are very important things in her life that she cannot be without, and anywhere she goes, she needs to have them. As a result, she is afraid to travel, and if she does not have her commode, she needs someone to pick her up and put her on the toilet seat. Even though he does not mind, she does not want her husband helping her with this when they are outside the home, especially when his family is present. She would prefer if he did not have to help her onto the toilet at all, and says that it makes her feel bad because he is her husband and not her caregiver and they want to maintain that relationship. Sometimes it is necessary for her to be away from her home all day, so her Doctor gave her a medication that prevents her from going to the washroom for 12 hours. She says the medication helps, but after nine hours she begins to experience spasms and

shivering, feels generally uncomfortable and becomes angered very easily. She lays down for an hour before she goes to bed and then empties her bladder so she can sleep through the night without having to get up to use the washroom. Sometimes it is hard to employ this routine if she has company over, or if her caregiver has left for the night. She did have some concerns related to leakage from her bladder prior to her accident as a result of having children.

Revelatory Phrases

The following are the revelatory phrases that have been identified from each woman's general description. The revelatory phrases have been classified into three categories: *sexuality*, *UI* and *blended*, which is a combination of the two topics.

1. Mary Cat

Sexuality:

1. She has never been 100% comfortable with herself in sexual situations. She says she is "sexually naive" because she lacks experience as her husband has been her only sexual partner. She felt she was lacking creativity and the ability to pull from other experiences when she became paralyzed because there were not any other experiences.
2. When she got back home after the injury, she was trying to adapt to her new life, and she did not think about sex for the first year.
3. It took so much effort to be in rhythm that it was more effort than it was worth, and putting so much effort into it made it so sex was no longer enjoyable. If she did the pros and cons of it, sex was more work than it was enjoyment. It was always hard for her to achieve an orgasm and she felt like she was not "achieving what she was supposed to" or "doing what it was all about," and that made her feel like a failure.
4. She says it is important not to have high expectations that things will be the same sexually as they were before because they "won't." You have to be honest, flexible and willing to experiment. If something is not working, do not take it as a slap in the face, try something else.
5. She has a few short relationships after her injury and after her marriage ended that were becoming sexual, but never went beyond kissing. She says these relationships were "just to see if she was still attractable to the male species."

Incontinence:

1. One day she was sick and was too weak to get off the toilet. She was afraid to go to the washroom after that in case she was not able to get off the toilet, and she was worried that she would lose her independence and not be able to live alone anymore. Her biggest concern is that she will have to be catheterized which she is not ready for and she does “not want to carry more things.”
2. Her urologic management program is “meh.” It is okay during the day, but she is incontinent during the night 98% of the time which is a pain and a lot of work to clean up because she does not like to be dirty so it is not just a quick wipe up, it requires a whole shower. Also, bladder infections increase UI and she cannot get away from the toilet.
3. Her frame of mind and nerves play a big part in UI. She has decided not to worry about UI anymore because whatever happens, happens, and since then her bladder has improved leaps and bounds.

Blended:

1. She was afraid that she would be incontinent during sex because it would be embarrassing and it would be extra work to clean it up, so it did not make it fun.
2. Her fear of UI has “killed her sexuality” because being incontinent while being intimate is not something she is willing to compromise on, and it is uncomfortable having a sexual relationship knowing that she will be incontinent. Even Prince Charming would not change her mind because to her, it just is not acceptable.
3. She knows the statistics about the importance of sex after SCI, but she does not agree with them because you can live without sex, but you cannot do without your bladder and bowels, so those things are more important to her. Someone told her that more important than sex, and even more important than walking is bladder control and she agrees with this. She does not put sex at the top of the list, but bladder is at the top of her list.

2. Caroline*Sexuality:*

1. Sex is very important to her, and to a relationship so that you can stay close and connected to your partner. Sex was important to her before the accident and she hoped that it would remain that way. She was in the intensive care unit with a trach, hooked up to life support when she asked about sex right away as one of the first things she was thinking about early on. When she asked, the nurse told her sex was not important and that she should be focusing on other things which freaked her out and she did not ask about sex again for a long time after that.
2. She was a little bit wild after her accident and had a few partners while trying to prove that she could still attract men, but during that time she was paranoid about her bladder,

bowels, and passing gas during sex because those things would be “totally embarrassing” so she calls those experiences “conservative sex” with no exploring. She was afraid she would ‘shit’ on someone’s face, and that was her biggest fear.

3. After SCI it is necessary to be more creative and to explore different ways to be sexually satisfied. Her and her husband have been ambitious that way and have tried pretty much everything. She gets frustrated because she cannot feel things the way she used to, and because it took her so long to have an orgasm.

4. Her injury made her want to get married even more because she wanted to be with someone who did not care about all her “stuff,” and so she would not have to explain bladder etc. anymore. She just wanted someone to love her forever.

5. Open and honest communication is even more important after SCI because there are more things to worry about, especially with sex.

Incontinence:

1. Urinary incontinence was constant in the first year after her accident. When she started taking Ditropan, the UI stopped instantly and happens only very rarely, about once a month. She only takes her Ditropan once a day even though she is supposed to take it three times a day. She says that is just enough to be effective without causing such overwhelming side effects that she cannot function properly, and that you have to find that balance.

2. Her urologic management program is quick and effective and she has tweaked it so it works for her, but it took her a long time to figure it out and UI is always at the back of her mind. Learning to pee on the toilet “gave her a lot of freedom.”

3. She has more UI when she has a bladder infection.

4. She will never forget when she “soaked” a guy when they were fooling around. She does not think she ever saw him again and she says you scare away all the guys that cannot handle it. If she was not married, she thinks that would be the worst thing about UI, but as a married person, UI in a professional setting is worse because people might not understand. She wants to be respected professionally, but she might lose that respect if she becomes “Mrs. Pee-Pee Pants.”

5. The thing that bothers her the most about UI is the “pain in the butt that it is to...get cleaned up,” (ie: change clothes, change chair cushion, etc.). She says that UI is an inconvenience more than it is embarrassing.

Blended:

1. She is afraid that she will have a bladder spasm while she is receiving oral sex and pee in his face which she says “isn’t hot.” She says there is a connection between the pleasurable sensations during oral sex and UI, and she is afraid to do things that feel good because for fear that UI may happen and that stops her from enjoying sex as much as she

should. This fear also made her more conservative in what she does sexually instead of just doing what feels good.

2. To avoid UI she goes to the washroom and catheterizes to make sure that her bladder is empty before having sex. This affects the mood by stopping the momentum and putting a damper on things.

3. The first time she was incontinent during sex with her husband, she let him believe that it was a g-spot orgasm because she did not want him to know what it really was. Luckily she was at home so she could wash the sheets.

4. Though being incontinent during sex with her husband is embarrassing, he never made her feel stupid about it, so she was able to get over it. Urinary incontinence is “still a little bit scary,” but it does not affect her sexuality anymore because her husband has “seen it all.”

5. She was funny about not telling anyone anything about UI and would give zero disclosure to a new partner. She wanted the guy to see her as a sexual person and not have the ‘thing’ that is on the guy’s mind be worrying if she is going to “pee on him.” She might be worrying about it, but she does not want him to be worrying about it.

3. Brooke

Sexuality:

1. The second thing she wanted to know after if she could still walk, was if she could still have sex, if she could still feel and enjoy sex, and if she would still be capable of having an orgasm. Sex was something she wanted and needed to be fulfilled.

2. She wanted to experiment sexually as soon as possible after the accident to get the answers to her questions, but her boyfriend said no because he thought she was too fragile and he did not want to hurt her. She has also been worried about being injured during sex and worries about where her legs are during sex because even if she can not feel it, she can still pull a muscle.

3. Before her injury she used to enjoy “romantic sex,” but now that she lacks feeling, she likes it rough with slapping and hair pulling. She would not have liked that before, but she loves it now because she can actually feel it. Sometimes this makes guys afraid because they do not want to hurt her.

4. Because she does not get attention from guys like she used to, she never walks away from it even if the guys are not the greatest. She did not think that she would ever be with another guy because she did not think that anyone would be interested in her. It was easy to find someone willing to make a relationship work before, but it is hard to find someone willing to make it work with someone who is in a chair.

5. Guys worry about being able to satisfy her sexually. They worry about the unknown and do not know what to expect or how to handle it. She tries to make it as easy as possible by explaining things which she does a lot and wishes she did not have to, and even if a guy is not pleasing her, she will make it seem like he is to be a nice person.

Incontinence:

1. She used to wear a brief but now she wears regular underwear. Even if they are granny panties it is still real underwear and that has helped her confidence and esteem greatly.

2. The brief made her feel like a baby or a grandmother.

3. Because she has a high spasticity bladder, UI is always a concern for her.

4. Since her bladder Botox she is not concerned, aware or nervous about UI. Her bladder is the best it has been in the past three years but it still is not the same as it was before, and there will always be that comparison. Despite all she has conquered, UI is still always on her mind.

5. She tells guys that lots of people experience incontinence, not just people with SCI who are in wheelchairs. She tells them that many women who have had babies have experienced changes to their bodies that result in UI, and guys consider them to be "MILFS."

6. She accidentally wet herself on a date which made her frustrated with herself and she was so angry that she had to deal with this while she was changing in the bathroom stall.

Blended:

1. Sometimes guys would not notice the wetness from UI until after sex was finished and they were sometimes unable to figure out what it was. They would ask if it was sweat, and she would say that it was so they would think it was something other than urine. Her biggest fear is being rejected and a guy not wanting to be with her because of the UI.

2. She carries a blanket in her bag of supplies that she lays down on the bed before sex and guys always comment on her level of preparedness. She has to tell them that things work differently for her and other people do not have to think ahead of time like she does.

3. Before the injury the only thing she worried about was if a guy was clean and sexually transmitted disease free, but now she has so many more things to think about that she did not have to think about before. She wishes that she could still be playful, but she has all these worries on her mind that she did not have before.

4. When her bladder is empty, she does not feel as much sexually, but when it is not empty, she cannot enjoy sex because her AD symptoms get in the way.

5. She did not have bladder infections before her injury, but now has them all the time. She worries about leaking during sex when she has an infection because the urine is darker, cloudy and has an odour which has the potential to be really embarrassing.

4. Clay

Sexuality:

1. Before foreplay could have been anything; dancing, undressing, role playing, but now it involves getting ready to have sex; being undressed and lubricated. It is a lot less playful and more about the task at hand, more about how it comes together than the romance. In the beginning she eliminated foreplay because so many things could go wrong or be noticed, so it was better to get on with it quickly before bladder accidents happened and to mask the body.

2. She has been frustrated when her mind is ready and she wants to get laid, but her body is not ready.

3. Being on the bottom during sex does not feel as good now as it did before because it is the only position she has got versus the one that she chooses. She likes to be on top and be in control. Being on top makes her body seem more useful and like her legs are not just good for nothing because they are weight bearing. She feels more normal because it is a position that an able-bodied person would do.

4. If she is really comfortable with someone, she might suggest that they try something new, but it is no longer in the heat of the moment, passionate way it had been before. Even still, she has blown her mind with what she has been capable of sexually.

Incontinence:

1. The worst thing about UI is peeing, but being clueless about it and not knowing that she is peeing. It is disturbing not to be the first one to know that your bladder is working and to have someone tell you that you are peeing.

2. She has been frustrated when her bladder or bowels were supposed to work but did not, and even worse, when they did work when they were not supposed to.

3. She hoped to learn to catheterize on the toilet which really changes things because it is one thing to go to the washroom and go pee, and another to ask the guy to please leave while you pee in the bed and then go dump it in the toilet. If she was going to date a guy, she at least wanted to be normal enough to pee on the toilet like everyone else.

4. Before the second injury, no matter how much she catheterized her bladder just liked to spasm, and during that time, she was guaranteed to pee during sex even if she has just gone to the washroom. She thought she would be single forever, that no one would love her, and so much for a sex life. During that time her bladder made her feel “not sexual.” She felt scary, gross, undesirable and ashamed.

Blended:

1. Foreplay was more calculated. She would pee, then they would play, then she would pee again, so two pees before actual penetration.
2. Her worst case scenario and the hardest thing to get over with UI would begin with a bladder infection, so stinky, smelly, cloudy, sediment filled urine, and then having incontinence while someone is giving you oral sex. As bad as it would be for her, it would be 10 times worse for the guy. It is one thing to be peed on during sex (which she does not think is that bad, probably because she has done it so many times), but it would be traumatic to pee in someone's face.
3. She once peed at the same time she had an orgasm and she was unsure if the peeing was what caused to orgasm. Because her sensation is very muted, it is difficult to distinguish between stimuli. After that, she would sneak her hand down when the sex was feeling really good to see if she was peeing which took away from the pleasure and the heat of the moment and replaced it with panic about what it really was.
4. She has a record of mostly successful sexual experiences without UI so that dictates how she feels, but there was a time when UI was her greatest fear. Her fear was not just felt if UI did happen, but just knowing that it could happen evoked those feelings. It made her heart race and went from being enjoyable, stress relieving, euphoric, and relaxing to something that caused anxiety and panic attacks. She was sweating and not because it was feeling good. She says its really sad when you are having sex and it is fear and worry you feel, and if that happens too often, you withdraw and no longer want to have sex because it stresses you out instead of makes you feel good.
5. Having those conversations about UI with a new sexual partner sucked, but had to happen for the relationship to evolve. It made her nauseous and nervous. It is one thing to have the conversation face to face, and another to do it butt naked. It is easier to take the rejection when you are fully clothed and in a different type of setting.
6. She was set up with a leg bag but she thinks that she probably would never have gotten into bed with a guy with a bag of urine attached to her leg.
7. She gave UI so much power that she could have great sex, but if it ended in UI, it would take away all the good and become a horrible experience. Having someone say it that it is okay is comforting, but it does not really make it okay.
8. Because of the UI she refrained from sexual activities and said that she probably would have had sex a lot sooner after her SCI if UI was not an issue. It stopped her from having sex when the moment was otherwise right, and delayed her from having sex altogether.

5. Sarah

Sexuality:

1. Without sex, P5 would not have a lot of touching or loving because her intimacy comes from sex and that is how she tells her partner she loves him.
2. She used to have sex anywhere, anyplace, anytime, but now sex happens only in the bed. Sex in other places and positions is just awkward. She never used lubricant before and lubrication would happen on command, but she does not get 'wet' like she did before. She wants to be the aggressor and to be on top because those things turn her on, but she cannot take charge without her boyfriend's help and she can no longer move well enough to be on top. As a result, sex now is less exciting because it is the same every time and has led to a decrease in sexual desire.
3. Her partner always wants to please her, but it is a lot of work and it can take an hour or two, so sometimes she fakes an orgasm. She would like to just 'wham-bam-thank you-m'am,' and she wonders if it is worth it all the work. Her sexuality has decreased since the accident because there is usually no happy ending and no explosion at the end. She does a lot of trying to make herself believe that she can feel things. She knows what sex used to be like and hopes that one day she can get that back. Because it is not as easy as it was before to be satisfied, she has tried new things sexually in the hopes of figuring out what will satisfy her.
4. She holds her legs during sex so they do not spasm because the least she can do is hold her own goddamned legs.

Incontinence:

1. Urinary incontinence affects her a lot and everything about it bothers her 'the most.' There is no control and no stopping it. There is no peeing on her own and she has to use a 'stupid' catheter all the time. She feels like a little two year old most of the time because she cannot hold it, or do anything about it.
2. She has learned to go to the washroom in her wheelchair and in her car because there are not a lot of public washrooms that are accessible to her. It bothers her that she always has to be aware of where the bathroom is and which one she can use.
3. Her urologic program is doable, but it sucks. She won't wear a diaper, and is worried about her leg bag bursting or overflowing.
4. The week she was off her bladder medications was her best week of feeling and she felt like a whole new person, but she cannot pee herself 24/7, so she had to go back on the medication.
5. At night if she has to go to the washroom she just does it in the bed because if she gets out of bed she wakes the whole house because her legs spasm and shake the bed and she might also make a grunting noise. It sucks and her boyfriend hates her for it.

Blended:

1. She feels more sexually if her bladder is full as opposed to if she has just emptied her bladder. Sometimes she cannot tell if she is coming or peeing because sometimes they feel the same. She will stop and check, but there is not usually any wetness there even if it feels like she has voided. As a result, she is concerned about UI when sex is feeling really good.

2. Urinary incontinence affects her sexuality because her boyfriend does not initiate sex because he thinks that she will say she has to pee, especially in the morning. She tries to go to the washroom before they engage in sexual activities, but sometimes they have to stop in the middle so she can void.

3. Urinary incontinence has not stopped her from participating in sexual activities because she has peed on her boyfriend so many times that it is not surprising anymore and he knows this is what might happen if he wants to have sex. Still, she feels totally ashamed like she wants to curl up into a ball and hide and never see him again because she feels like an idiot for peeing on him, and no one wants to pee on their partner. It is embarrassing for both her and her boyfriend. She does not think that anyone should be peed on and says that it is not pleasurable, so she does not want him to accept it because its not okay even if he says that it is.

4. She never thought of sex or bladder issues before the accident and things were 'easy-peasy' compared to now. She never put two cents into thinking about it, but now she has to think about it every day.

5. She is concerned that her boyfriend might leave her one day for someone who does not have so many issues and who can do everything because they are able-bodied. She wonders why he would want to put up with so much.

6. Jessica

Sexuality:

1. Sexuality is at the bottom of her list and she has no interest in it at all.

2. She is not frustrated with her lack of sexual relationship with her husband. She could care less and it is the last thing on her mind.

3. Talking about sex would be frustrating for her right now because she does not want a sex life so she does not talk about sex, think about sex, or have any feelings about it. She pushes it aside so it does not exist.

Urinary Incontinence:

1. She would have liked to have learned in rehabilitation how to cope with the embarrassment of UI which is her biggest concern.

2. She leaked and experienced UI when she was in public (in the lab at Brock University) which made her feel ashamed, dirty and awful because she does not consider UI to be normal. She wanted to crawl into a hole.

Blended:

1. She says that if she were to participate in sexual activities, she would be concerned about her bladder leaking because it definitely would which would make her embarrassed so UI does affect her sexuality.

2. It would not occur to her to have sex with her husband, or to even talk about sex with her husband because of UI which is the main reason she would not have sex.

7. Tina

Sexuality:

1. Her first question after the injury was if she could still have sex. She says that sex is very important to keep a relationship going, so initially when she thought they would no longer be able to have sex, she believed that their relationship would be “done.” P7 worried that her husband would leave her if she was unable to have sex with him.

2. P7 says that she thinks it is difficult for her husband to have sex with someone who has a disability, and she cannot move, so she just lays there.

3. At first she was afraid to have sex after the accident because she was scared that her husband would do something that would hurt her and she would not be able to control it because she has very little feeling.

Incontinence:

1. Her bladder is the biggest problem that she has right now.

2. She says her wheelchair and her commode are very important things in her life that she cannot be without. Anywhere she goes, she needs those things.

Blended:

1. Urinary incontinence affected her sexuality because she worried that if was accidentally incontinent during sexual activity her husband would not want to be intimate with her anymore.

2. Sometimes P7 wants to catheter because it would be easier to manage, but her husband does not want her to catheterize. She thinks this is because if he the catheter, he might find it unattractive and would no longer want to have sex with her.

3. She feels bad when her husband has to help her in the bathroom, especially in front of his family or other people, and she does not want him to help her because he is not her caregiver, he is her husband and they want to keep that relationship.

4. She still compares her sexuality and her bladder to before the injury and she says it is a huge change that has affected her very badly. Even so, she knows that her life is not over, so she tries to live with what she has now.

Themes

The following are the themes that have emerged from the revelatory phrases that were found in each woman's general description. The themes have been organized into same three categories as the revelatory phrases, those being *sexuality*, *UI*, and *blended*.

The themes in each category are listed below:

Sexuality	Urinary Incontinence	Blended
1. Sex: One of the first things asked about after injury	1. The worst aspects about urinary incontinence	1. Always the comparison to before spinal cord injury
2. The feeling that no one would ever want to be with her, and that no one would ever love her	2. Bladder infections: A big problem (Factors increasing urinary incontinence)	2. So many issues to think about that she did not think about before
3. Learning that she could still attract a man	3. Nerves and urinary incontinence	3. Concerns regarding infected urine and sex
4. Increased interest in marriage	4. The bladder management program: Room for improvement	4. Preparation and precautions for urinary incontinence
5. Concern that her partner may leave her for someone who is able-bodied	5. Negative effects of medications for urinary incontinence	5. Partner's reaction determines her feelings toward the phenomenon
6. The meaning of sex has in a relationship for a woman	6. Feeling like a "baby" or a "grandma"	6. Effects of urinary incontinence on sexuality
7. Her fear of being hurt during sex, and her partner's fear of hurting her	7. The bladder and urinary incontinence: A big part of her life	7. A possible connection between pleasurable sexual sensations and urinary incontinence
8. The evolution from "conservative sex" to "exploratory sex"	8. Issues with 'the toilet' and 'the washroom'	8. Disguising urinary incontinence as something else
9. Effects of decreased mobility on sex	9. "The sheets"	9. Disclosure

10. "Faking it" as a consequence of altered lubrication and sensation	10. Urinary incontinence: Less embarrassing with family and friends	10. Fear of rejection
11. Concerns about the ability to sexually satisfy one's partner		
12. Continued importance of sex		
13. Drug and alcohol abuse in the partner		

Sexuality:

1. Sex: One of the first things asked about after injury

Sex appears to be one of the top priorities for the women in this study as well as their partners. This is consistent with Anderson (2004) who found that sexual function was the highest priority in terms of functional recovery for paraplegics, and the second highest priority for tetraplegics. Often, one of the first issues the women in the current study inquired about after SCI was sex. The women wanted to know if they could still have sex, and how it would compare to sex before the injury. They had numerous questions regarding sexual function that they wanted to have answered as soon as possible. The answers they received brought a sense of relief, but there were still many additional questions that they felt had yet to be resolved. One participant stated that she did not agree with the importance that people place on sex after SCI, and that for her, the things that were crucial for survival, such as bladder and bowel function, were more important. Some of the existing literature in this area (Charlifue et al., 1992; Kreuter et al., 2008) has found that sex becomes less important to women after incurring a SCI, and as a result, sex was not among their most important concerns. Conversely, these interviews and other existing literature (Anderson, 2004; Reitz et al., 2004) have

demonstrated that sex does continue to be incredibly important for women after SCI. One of the participants in this study helped to close this gap by saying that sex had always been important to her, and even though it continued to be important post-injury, it was not her first priority. She felt that she had to focus on achieving other goals, such as being able to use a toilet and being able to drive, before she would be able to attract a man and to be worthy of an intimate relationship. The reason that sex was not her first priority was not because it was no longer important to her, but because she felt as though she needed these other abilities first in order to get to a point where sex was an option for her because it was still important.

Supporting Quotes:

Caroline

She asked about sex right away, and it was one of the first things that she was thinking about early on after her injury. She was in the intensive care unit with a trach and was hooked up to life support when she asked about it. When she was told that she could still have sex and that it could still be good it gave her a sense of relief, but she still had a million questions.

Brooke

The first things she wanted to know about after her injury were if she could walk, followed by if she could she have sex. She wondered if she would still be able to feel sex, enjoy sex, and if would she be able to have an orgasm. She had some confirmation regarding sexuality from her peer mentor which helped her begin experimenting sexually as soon as possible after the injury because she wanted to get answers to the questions she still had.

Tina

After the injury, her and her husband both thought that he would no longer be able to touch her anymore, so he told her to ask the Doctors about sex right away. Her very first question after the injury was regarding sex because it was important to both her and her husband.

Clay

She had always been a sexual person and it was important to her, but other things became more important after the injury, such as peeing on a toilet and driving, because she felt that she needed those things before she would be worthy of an intimate relationship.

Contrasting Quotes:

Mary Cat

She knows the statistics about the importance of sex after SCI, but she does not agree with them. She says that you can do without sex because it does not help you survive, but you cannot do without bladder and bowel function so those things should be most important. A man with SCI told her that more important than sex and even walking is bladder control and she agrees with that. She does not put sex at the top of her list, and says that it is her bladder that is at the top of her list.

2. The feeling that no one would ever want to be with her, and that no one would ever love her

The women were doubtful about any future romantic or intimate relationships because it was their opinion that no one would want to be with them as a result of their SCI. This was a legitimate concern as Pentland and colleagues (2002) found that the marriage rate is considerably lower for women with SCI than it is for the able-bodied population. The women in this study felt that they no longer possessed the characteristics that men were looking for, and that they would have to settle for any desperate man who would approach them. It has also been more difficult to maintain a relationship since being in a wheelchair, and that is consistent with previous research which found divorce and separation rates post-injury to be almost double that prior to injury (Charlifue et al, 1992).

Supporting Quotes:

Mary Cat

She was shocked when a man approached her and told her that he had been meaning to talk to her. She looked around to see if he meant someone else. At the end of another relationship, the man said to her that he was going to “go be with a real woman (who was not in a wheelchair),” and that negatively affected her self-esteem because no one likes to hear those things about themselves.

Clay

Now, when she looks in the mirror, she does not see the qualities that she would use to define what ‘sexually attractive’ means and she feels that she is missing some of the key components of sexuality. After the accident she thought that she would be single forever and that no one would ever love her. She thought “so much for a sex life” and that she would never have sex again. She initially thought that the men who were approaching her

after her accident must have already tried everyone else, and that they must be really desperate.

Brooke

She does not get attention like she used to so she never walks away from it, even if the guys who are giving the attention are “not the greatest.” After the injury, she wondered if she would ever have a boyfriend and if she would get married. She did not think that she would ever be with another guy because no one would be interested in her. She says that it was easy to find someone willing to make a relationship work before, but it is hard to find a guy willing to make it work with someone who is in a wheelchair. She feels that guys have taken advantage of her because they thought that no one else would want her, and that no one was going to sweep her off her feet and take her away.

3. Learning that she could still attract a man

In theme two, the women communicated that they felt as though no man would ever want to be with them after SCI, nonetheless, they were hopeful that they might still be able to attract a man. The women learned about their continued ability to attract men post-injury through brief relationships, being pursued by men, and by having multiple sexual partners. This verified to them that they were still appealing to men, that they were capable of having various types of relationships and that that option was still available to them.

Supporting Quotes:

Mary Cat

The two short relationships she had after her injury were just to see if she was still attractable to the male species.

Caroline

She was a little bit wild after her accident and had a few sexual partners while trying to prove that she could still attract men.

Clay

After the accident she did not have the confidence to approach men, but when they started “picking (her) up” she realized she was still in the game.

4. Increased interest in marriage

A number of the women became more interested in marriage post-injury. They wanted to be with someone who already knew about all of their issues so they could stop explaining bladder function and sexual function, among other things, and so they would no longer have to worry about rejection as a result of SCI related challenges. They were looking for someone who knew about all of their issues and who would still accept them anyway. When they thought that they had found a man who could be that person, they wanted to “scoop him up.” One of the seven women who had been married prior to her injury and who had divorced post-injury did not agree with this. She was no longer interested in relationships because she did not want to deal with the emotions that come with being close to someone, and she had chosen to make herself the priority and focus all her energy there.

Supporting Quotes:

Caroline

Before her injury, she hoped that she would one day get married, but the injury made her want to get married even more. She wanted to be with someone who did not care about “all her stuff.” She wanted to get married so she would not have to explain bladder and bowel function anymore because it would no longer be an issue. Urinary incontinence does not affect her sexually anymore because her husband has already “seen it all.”

Clay

She is now engaged, but before the injury she did not want to get married. She likes to think that SCI did not play a factor in changing her mind, but she has caught herself thinking that she better scoop this guy up because he may be the one and only person who accepts her the way she is.

Sarah

Because she has peed on her significant other, among other things, he is no longer surprised when it happens. He is aware that this situation may occur if he wants to have sex, and he is okay with it. They both come from broken homes, so they are sceptical of marriage. Though they are not technically married she chose to have a baby with him and that, in her mind, makes them ‘married’ because now they are tied to each other forever. In the past, she had had multiple abortions with her ex-boyfriend because she knew that she did not want to be with him forever.

Brooke

She will explain sexual function to guys which she finds herself doing a lot and she wishes that she did not have to, so at this point she is only interested in relationships that have marriage potential.

Contrasting Quote

Mary Cat

She is not interested in a relationship right now because it would be too much work, she is not willing to go through the emotions, and her bladder is much worse than it used to be. She does not miss or need a relationship in her life because she has other things going on. Being single is a preference because she is only committed to herself and since her energy is limited, she can spend it on herself and does not have to waste it on things that “don’t matter, like a relationship.”

5. Concern her partner may leave her for someone who is able-bodied

The women were concerned that their partners would leave them for someone who was able-bodied, and therefore, who had fewer issues. As a result of the SCI, their own feelings that they were “defective” and that they would be unable to give their partners everything they needed, combined with lowered self-esteem made them question why someone would choose to be with them. They feared that their partners, who in their opinions could be with any women they chose, were going to leave them for women who were not disabled.

Supporting Quotes:

Mary Cat

She says that her divorce was not totally caused by the SCI because her and her husband had a number of other problems, but the injury put her husband into overload and that is when their marriage ended.

Caroline

She was in a casual relationship at the time of her accident and she thinks that that relationship ended because she farted in front of the guy and he freaked out. She remembers a horrible sound coming from her body and she was horrified that he was there. She says that after that, he disappeared. She says there were probably other things, and that he was probably afraid of everything that went along with the fart. Her mom is very supportive and said ‘if he can’t handle the farts, how is he going to handle the poo?’

Brooke

She worried because her boyfriend could be with any girl so why would he want to stay with someone who is in a wheelchair and who is a “defect,” or “defective?” She says that they did not want to break up and thinks that without the injury, they would still be together. Now, when guys are interested in her she says to them ‘you know I’m in a chair right, not just for part of the day, its permanent and a permanent disability.’

Sarah

When she became injured, she had been with her boyfriend at the time for approximately five years but he was not accepting of her injury and she says that he just wanted it (the wheelchair) to go away. He wanted things to go back to when it was all about him and was a big part of why they broke up. She is now concerned that her current boyfriend may leave her one day for someone without so many issues and who is able to do everything because she would be able-bodied. The thought that he might leave her has always been in her mind and she wonders why he would want to put up with so much. She has to put up with it because it happened to her, but he could walk away.

Tina

She was very scared that her husband was going to leave her after the accident if she was unable to have sex for someone else who could.

6. The meaning of sex in a relationship for a woman

For these women, sex is about more than just the physical aspect. Sex is a way of forming and maintaining a close connection with her partner, and a means of being with him in a way that is different from the way she interacts with any other man. It is a way for her to communicate the feelings that she has for him.

Supporting Quotes:

Caroline

Sex is important in a relationship to stay close and connected with your partner.

Clay

Sex is something you do with someone who is more meaningful than the average person.

Sarah

She does not describe herself as a “love-dovey” person, so her intimacy and the way that she says “I love you” comes in the form of sex.

Tina

Being intimate and having sex is a very important part of a relationship, and it is necessary to keep the relationship going. Having sex allows her to be close to her husband, and without it, he would just be like any other person.

7. Her fear of being hurt during sex, and her partner's fear of hurting her

The women were fearful of incurring an injury during sex. If something was hurting her, she may not be able to feel it, and she would therefore be unable to stop it from happening. This concern was often times shared by the partners of these women as they were fearful of the unknown and were unsure about how to be intimate with someone who had a SCI. Another fear that the women had was the fear of experiencing AD during sexual activities. Some of the women had been warned by their Doctors about the possibility, and that made them afraid to have sex. AD was also something that was very concerning to the partners of these women.

Supporting Quotes:

Clay

She held back information on AD because it was “scary,” and when it did happen, the response of her partner was typically worry and panic. He would become concerned about doing something that would cause her to go autonomic, and that would take away from the moment. She also thinks that her fiancé might be concerned about hurting her during sex, and says that that is no different from her own concerns regarding their sexual life.

Brooke

She wanted to begin experimenting sexually soon after the injury because it was important to her, but her boyfriend said “no” because he thought that she was too fragile and he did not want to hurt her. Since she now enjoys “rough” sex, guys are sometimes afraid to do the things she directs them to do because they do not want to hurt her. She herself worries where her legs are during sex because even if she cannot feel it, she can still pull a muscle.

Tina

After the accident, she did not know what things she was allowed to do sexually, and the Doctors scared her by telling her that she could experience AD as a result of participating in sexual activities. She was scared at the beginning and found it difficult to have sex because she was worried that her husband would do something that would hurt her, and that she would be unable to control it because she would not be able to feel it.

8. The evolution from “conservative sex” to “exploratory sex”

Sex after SCI began conservatively as the women learned what worked for their new bodies and abilities, and what they could feel and what caused problems. With increased experience, and as they became more comfortable with their sexual partners, sex became very exploratory. Due to decreased sensation, it became necessary for the women to be more creative and to try novel sexual activities to be satisfied which had also been suggested in the study by Kreuter, Siösteen and Biering-Sørensen (2008). Most of the women felt that it was even more necessary after SCI to get to know someone before being intimate, and having that level of comfort made things a lot easier.

Supporting Quotes:

Caroline

She calls the initial sexual experiences after SCI “conservative sex with no exploring,” but since then, the SCI has forced her to do more explore about how to be sexually satisfied. She has become more creative, and her and her husband have tried “pretty much everything” while exploring what feels good. They have been ambitious that way, and her husband is open and willing to try things.

Clay

Sex after the injury started with her just being on the bottom, but she surprised herself with what she would do sexually, and has blown her mind with what she has been capable of. Spinal cord injury and resulting UI really forces you to get to know someone before being intimate. Before the injury she would date someone for a month before sleeping with them, but after her injury it was more like five or six months because there was a lot of information to share to get them prepared and make sure they were “still game” given everything. It took her a long time to try different positions after the injury and it was only after she was really comfortable with someone that she might suggest they try something new, but it was not in the same “heat of the moment” way it had been before.

Sarah

She has varied her sexual repertoire since SCI because there are more issues to work around and it is more difficult to be sexually satisfied which has led her to try new things. She is not sure that she ever would have become this open sexually if it were not for the injury.

9. Effects of decreased mobility on sex

Sex post-injury is very different than it was before SCI. It is less spontaneous and requires more planning. Foreplay is different in that it has become more about “getting ready to have sex” than about increasing sexual desire. There is also less time spent partaking in foreplay as the women prefer to get to intercourse as soon as possible before issues with the body arise. Sex before the injury could have occurred in countless places and positions at any time, but that is no longer the case. A number of the women said that trying to have sex in different places and positions is just “awkward.” The women seem to enjoy being on top during intercourse. They take pleasure in being in control and being able to direct the movement in a way that feels good for them, but most of the women are no longer able to be on top due to decreased mobility. The women discussed the usefulness of their bodies and for them, being able to be on top holds a great deal of meaning because it makes the body feel more functional, and it makes them feel closer to “normal” because they are having sex in a position that an able-bodied person would have sex in. Some of the women said that they just “lay there” during sex or that they do very little work and this is not okay for the women who consider themselves to be adventurous. Overall, it seems that sex has become less exciting after incurring SCI because it is mostly invariable, and this is frustrating for both the women and their partners.

Supporting Quotes:

Clay

Before the injury, she would have sex anywhere and in all kinds of positions but since the injury, sex has become somewhat awkward and difficult. Sex is very different now in terms of the way she undresses, and she wonders how a mostly paralyzed person undresses in a sexy way. Before, foreplay could have been anything; dancing, undressing, role playing, etc., but now it is more calculated and involves “getting ready to have sex;” being undressed and lubricated. She has since eliminated foreplay because so many things could go wrong or be noticed, so it is better to get on with it quickly before bladder accidents happen, and to mask the body. It is a lot less playful, and more about the task at

hand, and it is less about the romance, and more about how it all comes together. Positions have changed because her body does not “hold,” and there is no standing or bending. At one point in her injury she was able to get to her hands and knees which was great because from there she could get on top. It was a lot of work, but being on top is her favourite position because they move at her pace and go at her depth. She thinks being on top and being in control is sexy. It also makes her body feel more useful, like her legs are not just “good for nothing” because she is weight bearing in a position that an able-bodied person would do, and that makes her feel more “normal.” It was okay for her to be on the bottom before the injury because she *could* be on top, but now being on the bottom does not feel as good because it is the only position she has, versus the one that she chooses. She considers herself to be the adventurous type, so it is not okay for her to just lay on the bottom.

Sarah

Before her accident, she would have sex “anyplace, anywhere, anytime,” but now sex happens only on the bed because it works logistically. Her and her boyfriend have tried to have sex in various places and positions but it is “just awkward,” and she can no longer “duck into a bathroom” or stand in the shower to have sex. She would like to be the aggressor, to be on top, in charge and able to just “sit on him and go” because it turns her on to be in control, but she can no longer do any of these things without his help. She holds her legs during sex so that they do not spasm and she says “the least I can do is hold my own goddamned legs!” She no longer has enough movement to be on top and says that sex is less exciting now because it is almost the same every time. For these reasons, she is frustrated sexually.

Tina

She thinks that it is difficult for her husband to have sex with someone who has a disability. Sex is not the same as it was before because she no longer has the muscles to move so she just lays there and does very little. She says their sex life is “okay” and that her husband is okay with what they have now, but that maybe later he will not be okay with their intimate relationship.

10. “Faking it” as a consequence of altered lubrication and sensation

Sensation and lubrication are often affected by SCI and can negatively impact sexual function. Difficulty becoming lubricated, decreased sensation and not being able to feel sexual activities the way they did before can make the sexual experience frustrating and the women wondered if it was worth all the time and effort. Due to changes in sensation, the women may take pleasure in more aggressive sexual activities because they enjoy the fact that they can actually feel it. It has been well established in

the literature that it becomes more difficult for women to achieve orgasm after SCI (Siosteen et al., 1990; Tepper et al., 2001; Benevento & Sipski, 2002, & Kreuter et al., 2008). As a result of the difficulties the women in the current study now experience with lubrication and the ability to achieve orgasm post-injury, it requires a great deal of work, more than before the injury, to climax and they may fake their orgasm out of frustration, or to please their partner.

Supporting Quotes:

Caroline

She gets frustrated sexually because her sensation has changed since the injury and she cannot feel things the way she used to. She was also sexually frustrated because it took her so long to have an orgasm after the injury.

Clay

She says that she is lucky in terms of lubrication because it tends to be responsive and appropriate most of the time, but it is more difficult since her accident. She has been frustrated when her mind is ready and she “wants to get laid,” but her body is not ready.

Sarah

Lubrication used to happen on command, but that is no longer the case. She has some feeling, but it requires more stimulation than before the injury, and she says that sex does not necessarily have the “happy ending” that it used to. There is no “explosion” at the end, and she spends a lot of time trying to make herself believe that she can feel things. It could take her an hour or two to climax and sometimes she is too tired to continue and would rather just go to bed. In this case, she will occasionally fake an orgasm to make her partner happy. Sometimes she just wants to “wham-bam-thank-you-m’am,” and move on, but everything from becoming lubricated to achieving an orgasm is now more work and she is unsure if it is worth it.

Brooke

Her sexual activities have changed in a huge way since the injury because she used to enjoy “romantic sex” but now that she lacks feeling, she likes it rough with slapping and hair pulling. She would not have liked this before, but now she loves it because she can actually feel it. Guys do not know how to handle her body so even if he is not pleasing her, she will make it seem like he is to be nice. She still worries that sex will never be the same or feel the same.

11. Concerns about the ability to sexually satisfy one’s partner

The women became more concerned about their abilities to sexually satisfy their partners post-injury just like the women in the studies by Singh and Sharma (2005) and Kreuter and colleagues (2008) had. This concern seemed primarily to be caused by their now limited mobility and function, but was most likely also related to the feelings they had of being less attractive than they were before due to the toll that SCI had taken on their bodies. The women were not the only ones who felt this way. Their partners shared this concern because they were simply just unsure about how having sex with someone who has a SCI would work. They may have even experienced increased difficulty sexually satisfying their partner because it can be challenging to find ways to pleasure a woman with SCI due to decreased sensation.

Supporting Quotes:

Mary Cat

She feared that she would not be able to sexually satisfy her partner after the injury.

Sarah

Even though she can please her boyfriend any time of the day, she says that she cannot give deep massages or hand jobs as good as she did before because she is a tetraplegic and she does not have the muscles in her hands to do so.

Brooke

She says that guys are concerned they will not be able to satisfy her sexually, and she also worries about her ability to please her partner.

12. Continued importance of sex

Almost all of the women stated that sex had been important to them prior to their injury, and that it continued to be important to them afterward. Sex also continued to be an important part of their relationships post-injury. Singh and Sharma (2005) have also found that many women remain interested in, and understand the importance of sex post-injury as 72.5% of the women in their study remained interested in sex, and 87.5% understood its importance. That being said, the women were split regarding the frequency

of sexual activity. Some of the women said that they have “a lot” of sex post-injury and others said that while they still have sex, it does not occur as frequently as it did prior to their injury. For one woman, it appeared as though the frequency of sexual activity had decreased for the reason that sex had become more difficult because of her limited mobility. For the other woman, the decrease was attributed to a lack of sensation, and therefore not experiencing as much sexual pleasure as she had before. One woman stated that sex was not a key component of her relationship with her husband before the injury, and since the injury, sex was no longer a part of their relationship at all. She did say that if her sensation returned back to “normal,” then she would be more interested in renewing their sex life. Sex was important to the women before their injury and they continued to understand the value of sex in their lives and relationships post-injury, but even still, in some cases, changes to mobility and sensation as a result of SCI resulted in a decreased frequency of sexual activity.

Supporting Quotes:

Caroline

Sex was important in her life before the injury, and she hoped that it would remain that way after. At present, her and her husband are still happy and they have a lot of sex. Sex is a very important part of their relationship.

Clay

She considered herself to be a very sexual person before the injury and she is now 15 years post-injury and has had “a whole lot of sex.”

Sarah

Being a sexual person continues to hold a lot of meaning for her, but her sexuality has “gone down” since the accident because “it isn’t the same because there isn’t an explosion at the end.”

Brooke

She was willing to be with new guys after the injury despite all the body issues because sex was something that she wanted and needed to be fulfilled.

Tina

She has learned the value of sex and believes that it is important for men and women to enjoy sex because it is a part of life, and it is a very important part of a relationship. In spite of these feelings regarding the importance of sex, she says that her and her husband do not have sex as much as they used to before she became injured.

Contrasting Quotes:

Jessica

Sexuality was a part of her and her husband's relationship right up until the injury, though it was not a huge part. Since the injury, sex is no longer a part of their relationship, and she has not participated in any type of sexual activity. If she got sensation back, she would be more interested in sex.

13. Drug and alcohol abuse in the partner

Two of the seven women who were interviewed had partners that turned to drug and/or alcohol abuse to deal with the affects of their SCI. Both of these women were in serious, long term relationships at the time of their injuries; one had been in a committed relationship with her partner for four years and they had planned to be married, and the other had been married to her partner for eight years. It is plausible that the stress of seeing one's partner go through the challenges of SCI, taking on excessive responsibility and doing everything possible to aid with their adjustment, and feeling responsible for their accident may lead some individuals to turn to unhealthy means of coping.

Supporting Quotes:

Mary Cat

The accident was a huge strain on her husband and he began drinking and using drugs. He gave her his all to get her back on her feet, but it lead to his demise.

Brooke

Her boyfriend did the best he could, but he felt responsible for her accident and he could not handle it. He became depressed and ended up in rehabilitation for drug use.

Urinary Incontinence

1. The worst aspects about urinary incontinence

Among the top concerns related to UI were the clean up, the embarrassment, and the uncertainty. A number of women used the word “dirty” when talking about how UI made them feel, and with regards to the clean up, they said that it was quite time consuming, a lot of work and an inconvenience. Most of the women discussed the embarrassment experienced as a result of UI. Throughout the interviews, it became clear that this embarrassment was in large part based on the fact that the women did not consider UI to be “normal,” and had associated it with other emotions such as shame. The last theme regarding the worst things about UI was uncertainty. Not knowing when UI was going to happen, and sometimes not even being aware that it was happening was a major concern.

Supporting Quotes:

Mary Cat

She hates not knowing when UI will happen and says that UI is “embarrassing.” Being incontinent is a pain and a lot of work because she does not like to be dirty so for her it is not just a quick wipe up, it is a whole shower to be clean again.

Caroline

The thing that bothers her most about UI is the pain in the butt that it is to change her clothes, to change her chair cushion and to get cleaned up. It is an inconvenience more than it is embarrassing because she can hide UI when she is sitting in her chair, but it is always a pain to clean up.

Clay

The worst thing about UI was peeing, but being unaware that she was peeing, so not only was she peeing, but she was clueless that it was happening. She says it is “disturbing not to be the first one to know that your bladder is working and to have someone tell you that you are peeing.” It is frustrating when her “bladder and bowels are supposed to work and don’t, or worse, if they do work when they aren’t supposed to.”

Jessica

Embarrassment is her biggest concern regarding UI and she wishes that they would have addressed ways to cope with the embarrassment of UI when she was in rehabilitation.

She was at Brock University when someone said something funny to her and “Niagara Falls.” It made her feel so awful, ashamed and embarrassed, like she wanted to crawl in a hole because UI is not “normal.” She just wanted to go home because she felt dirty.

2. Bladder infections: A big problem

(Factors increasing urinary incontinence)

Many of the women stated that they had not experienced bladder infections prior to becoming injured, but now encounter them frequently post-injury. They also stated that a bladder infection is the number one factor that increases their likelihood of experiencing UI, followed by the type and amount of beverages they consume (see “Preparation and precautions” in the *Blended* section).

Supporting Quotes:

Mary Cat

Bladder infections increase the chance of UI, and when she has an infection, she cannot get away from the toilet.

Caroline

She has more incontinence if she has a bladder infection, and she is aware that consuming alcohol increases her risk of UI.

Clay

For her, drinking alcohol is the only thing that increases her UI.

Sarah

She has more UI when she has a bladder infection. The fewer bladder infections she has, the better she can control her bladder and the more “normal” she feels. She also said that alcohol, especially beer, increases the amount of UI she has.

Brooke

The main factor that increases UI is if she has a bladder infection which she never had before the accident but now has all the time. She also notices that she has more incontinence if she has been drinking alcohol.

Tina

Bladder infections increase the frequency of leakage from her bladder.

3. Nerves and urinary incontinence

The women revealed that the actual amount of UI they experience seems to be related to their nerves and thoughts regarding UI. The more they worry about UI, the more incontinence they experience. One of the ways the women have learned to reduce UI is to spend less time dwelling on it, and to just accept and deal with whatever happens.

Supporting Quotes:

Mary Cat

She believes that her bladder issues have a lot to do with nerves. Ever since she decided not to worry about UI and to adopt the mentality that ‘whatever happens, happens,’ her bladder has improved leaps and bounds.

Tina

If she thinks about incontinence too much her brain will send signals “there” and UI will happen, so she tries not to think about, or worry about it.

4. The bladder management program: Room for improvement

The women recognize that their bladder function could be worse, and as a result, they are somewhat satisfied with their bladder management programs. Though they have achieved some level of contentment with their bladder programs, they state that it took an exceptionally long time to reach this level of satisfaction, that there is still room for improvement and that they hope their bladder programs continue to develop and get better. Two of the women relayed that they now experience UI “rarely.” For one woman, this meant once a month, and for the other woman it was once a week. Though this may be the meaning of “rarely” in regards to UI for these women, if an able-bodied woman began to experience UI this frequently, she may consider it to be anything but rare.

Supporting Quotes:

Mary Cat

Her urologic management program is “meh,” and works for her only during the day. She is incontinent 98% of nights which is a pain and a lot of work, but she is unwilling to take more medication to help with the UI that she experiences during the night because she does not want to change the way her bladder operates during the day. She says her bladder could be worse as it is the day time that counts and UI is not a concern during the day

Caroline

Her bladder management program is now quick and effective because she has tweaked it so it works for her, but it took her a long time to figure it out. She says that she experiences UI very rarely now and it happens approximately once a month.

Clay

She is very satisfied with her current bladder management program because after all these years she has a pretty good handle on her bladder, but it took her a long time (10 years) to get to this point. She is now incontinent once a week which she calls “rarely.”

Sarah

Her bladder management program is “doable, but it sucks.” There is no control of her bladder and no stopping UI. There is no peeing on her own and she has to use a “stupid catheter all the time.” She says that she “will not wear a diaper.”

Brooke

Since having bladder Botox, she is very satisfied with her bladder management program, and it is the best it has been in the past three years but it is still not the same as it was before and there will always be that comparison.

Jessica

Her bladder management program is starting to work, but there is definitely room for improvement.

Tina

Her bladder could be worse so she is happy with her bladder management program, but she hopes that it gets better.

5. Negative effects of medications for urinary incontinence

Previous research has discussed the troublesome and frequently occurring side effects caused by UI medications (Sahai, et al., 2005; Wefer et al., 2010). The most effective medication these women used for UI was associated with a number of adverse side effects that made normal everyday functioning difficult. The women had tried other medications with fewer negative side effects, but they were not sufficiently effective in controlling UI. The women tended to experiment with their dosage until they found what worked best for them so that their UI was somewhat managed without causing such impeding side effects.

Supporting Quotes:Caroline

1 She takes Ditropan but takes it as infrequently as possible because of the side effects. She is supposed to take it three times a day, but takes it only once which is just enough to be effective without creating such overwhelming side effects that she can no longer function properly. She says that “you have to find a balance.” She has tried other medications, but they did not work.

Sarah

The medication she currently takes for UI causes a number of adverse side effects that she says affect her sexuality by causing sleepiness and “stopping sexual feeling.” She has tried to take herself off this medication, and she has tried switching to another medication with fewer known side effects. She calls those times her “best weeks of feeling” and says that she felt like a “whole new person.” Unfortunately, that medication did not “hold” and because she cannot pee herself “24/7,” she had to go back on the medication that caused the negative side effects.

6. Feeling like a “baby” or a “grandma”

Often times, incontinence is associated with infants who have not yet learned to control their bladders, or with the elderly who have lost the ability to control their bladders. Many of the women in this study revealed that they wear adult diapers to deal with the leakage that they experience. Since diapers and UI are most commonly associated with babies or older adults, it would be reasonable to suggest that able-bodied individuals who are unaware of the consequences of SCI may not understand why these women are experiencing UI and might compare them to babies or older adults. Even the women themselves stated that often times they feel like a “baby” or a “grandma” as a result of both the diapers they wear and the UI.

Supporting Quotes:Sarah

She feels like a little two year old half the time because she is unable to “hold it” or do anything about it.

Brooke

She always wore a brief (diaper) and that made her feel like a baby or a grandma. She was always terrified that the person she was with would notice it because of the sound

they make, or that he would feel it if he touched her butt which she would not be able to feel. She says that “now I can definitely say that I do wear regular underwear.” Even if they are just granny panties, they are still regular underwear and that makes her a lot more comfortable around guys.

7. The bladder and urinary incontinence: A big part of her life

Since incurring their injuries, UI has become a major concern for these women. They began to experience bladder issues right away, and no matter how far they have come in terms of their bladders, UI is still something that is always on their minds and that has a significant presence in their everyday lives.

Supporting Quotes:

Mary Cat

Thirty-four years post-injury she is still definitely concerned about her bladder issues that she had since the beginning right after her accident.

Caroline

The body issues that concern her are bladder and bowel related. She is always a little bit worried about them, and they are always at the back of her mind.

Clay

Her bladder has come a long way, but it is still a concern for her because it is always at the back of her mind.

Sarah

Urinary incontinence “takes up a lot of (her) life and affects (her) a lot.”

Brooke

Despite all that she has conquered, UI is still always on her mind. It is always a concern, and she worries about accidentally voiding if she cannot get to a washroom.

8. Issues with ‘the toilet’ and ‘the washroom’

Learning to go to the washroom on the toilet has been important for these women. Having the ability to do so increases the number of places, and the types of places that they can go. It helps to maintain independence, and positively affects their feelings of being ‘normal’ because they are using the toilet the way an able-bodied individual would. The women have identified issues regarding public washrooms that include toilets that

are too low to the ground which are difficult and sometimes even impossible to get off of independently, as well as a lack of public washrooms that are accessible to them.

Supporting Quotes:

Mary Cat

She was feeling sick at work one day and was unable to get off the toilet on her own. It took three firefighters to help her off. After that, she got a commode and had the toilet in her home elevated, but she was afraid to go to the washroom incase she was unable be able to get off the toilet. When she goes out she is always afraid that she will see a toilet that is too close to the ground and that she will have to call for help to get off the toilet.

Caroline

She had one nurse who she thanks very much because she made sure that she learned to pee on the toilet. This gave her a lot of freedom because she is able to go to the washroom in places that are not accessible.

Clay

She feels segregated and says that for the first time in her life she knows what the Black people felt like because she is not allowed in certain washrooms as they are not accessible to her. She says that you hope to learn to catheterize on a toilet because that really changes things. It is one thing to go to the washroom to pee, and another to ask the guy to “please leave the bed” while you pee in a plastic bin and then dump it in the toilet. If she was going to date a guy, she at least wanted to be “normal” enough to pee on the toilet like everyone else.

Sarah

When she goes out, she has to learn where the washroom is and make sure that she does not go too far from it. It bothers her that she always has to be aware of where the washroom is, and which one she can use. It would not bother her as much if she could just go on the toilet. She has learned to go to the washroom in her chair and in the car because there are not a lot of public washrooms that are accessible to her.

Brooke

There are certain places that she cannot go and there are always washroom accessibility issues.

Tina

It is hard for her to transfer onto the toilet, and she needs someone to help her by picking her up and putting her there. Her husband does not mind helping, but she would prefer if he did not have to help with this because he is her husband, not her caregiver, and they want to maintain that relationship. It bothers her even more when they are outside the home, and when his family is present.

9. “The Sheets”

Though the women in the study were never asked any questions regarding sheets, many of them provided some commentary that was centered on “the sheets.” This is an example of finding the meaning in the mundane. The sheets, an ordinary, everyday item have become representative of the experience of the phenomenon and the feelings toward it. The wetness on the sheets becomes evidence of UI, but urine on her own sheets is not nearly as embarrassing as urine on her partner’s sheets. It is easier to move past UI on her own sheets because she is the one who will be washing them and her partner will not be the one left cleaning up her mess. Having to clean the sheets is another reminder the things she has to deal with now that she never had to worry about before, and the work involved in cleaning up the mess afterward may be something that takes away from the enjoyment of the experience.

Supporting Quotes:

Mary Cat

Having to change the sheets after sex when she had been incontinent was extra work, and that did not make sex fun.

Caroline

Thankfully, the first time she was incontinent during sex with her husband they were at her home so she could wash the sheets.

Brooke

Her worst case scenario with UI was when she was accidentally incontinent on her partner’s bed that he had just bought and was very proud of. She apologized and they stripped the bed as quickly as they could. The guy said that it was alright because the mattress was okay; she wanted to leave. Most of the time when she is having sex it is at the guy’s home and UI is more embarrassing because it is in his bed, and on his sheets which she will always offer to wash.

10. Urinary incontinence: Less embarrassing with family and friends

The women in this study feel that UI is less embarrassing when it happens around family and friends than if it were to occur in front of colleagues. This is because the women feel more comfortable with their family and friends who have already seen it all

and even expect UI, and because these relationships are “non-conditional.” They worry that other people may not understand, or be accepting of UI, and that worry that they may lose the respect of their colleagues and business contacts. The first supporting quotation was given by a woman who is not at all interested in relationships at this time, and the second quotation was from a woman who is already married. As the second woman began to touch on, it is quite possible that even more embarrassing than being incontinent in front of business colleagues would be UI in front of a new sexual partner. However, neither of these women are in a situation to have a new sexual partner, and UI in front of family and/or friends still stands as the least embarrassing case scenario.

Supporting Quotes:

Mary Cat

Her worst case scenario with UI was when she was out having dinner with people from work and she did not make it to the washroom in time. She says this experience would not have been so traumatic if she had of been with friends as opposed to work colleagues because her friends are aware of her situation and her friendships are non-conditional. She says that she is lucky that her friends do not think of themselves as caregivers, just friends.

Caroline

Urinary incontinence would be most embarrassing in front of colleagues or clients rather than in front of family or friends. Professionally, she wants to be respected and she might lose that respect if she becomes “Mrs. Pee-Pee Pants.” She is comfortable with her family and friends, and because they are very used to her UI, they are no longer affected by it. She says that if she was not married, UI in a new sexual relationship might be the worst case scenario, but as a married person, the worst thing is professionally.

Blended:

1. Always the comparison to before spinal cord injury

No matter how long post-injury a woman is, there will always be the comparison to the way things were before her injury. The comparison to ‘before’ is made in many aspects that make up who she is and what she took for granted, but the comparisons these

women talked about most specifically were related to sexual function, bladder function and body image. Pre and post-injury comparisons are difficult to make because even though the injury might be the most obvious source of change, it is not the only factor involved. As time post-injury is increasing, so is age and the aging process itself will cause changes to body form and function. A number of the women acknowledged this fact and addressed it by stating what percentage of the changes they felt could be attributed to normal aging, and how much was as a result of the SCI.

Supporting Quotes:

Mary Cat

She says that the changes she has been experiencing may be in part due to age, but age is just a number and it is more about your mind and how you feel. She does not feel her age and does not think that aging happens over night, so she says it mostly due to the SCI

Sarah

She remembers what sex and orgasm used to be like before her injury, and she hopes to get that back one day.

Brooke

She will always compare herself to what it was like before, and everything that she took for granted. No matter how old she is she will always be comparing herself to when she was 21 which is difficult because of the natural changes that happen to a body with aging.

Jessica

She feels that at least 75% of the changes to her body have been caused by her SCI, and that the remaining 25% could possibly be accounted for by aging.

Tina

To this day she compares her bladder and sexual function to before the injury. It is a huge change that has affected her “very badly.”

2. So many issues to think about that she did not think about before

The women seemed to be quite perturbed by the fact that there are now so many issues that they have to think about and deal with everyday that they were not even concerned about before their injury. These issues are related to both UI and sex, among

other aspects of everyday life, and they discuss how much easier life was prior to their injury.

Supporting Quotes:

Caroline

She says that after SCI there are so many more things to worry about, especially with sex.

Brooke

Before the injury her only concern was if a guy was sexually transmitted disease free, but now she has so many more things to think about that she never thought about before. It has caused a lot of bad emotions and it is a drastic change. She wishes she did not have to worry about these things because she did not have to worry about them before and it used to be so much easier. She wishes she could still be playful, but she has worries on her mind that she did not have before.

Sarah

She never thought of bladder, sex or any of these issues before the accident and says that it was “easy-peasy” compared to now. She never put two cents in to worrying about these things before, but now she has to think about them every day.

Jessica

The first thing she asks when she goes out is where the washroom is, but she never thought about the location of a washroom before the injury.

3. Concerns regarding infected urine and sex

The number one factor the women say increase UI is a bladder infection. They become more fearful of UI when they have an infected bladder not only because there is an increased risk of experiencing UI, but also because UI during sex would be worse with an infection than it would be otherwise because now the urine is darker and has an odour. Something that was brought up and that could perhaps be the most embarrassing situation would be to have a bladder infection, and then to be incontinent while receiving oral sex.

Supporting Quotes:

Caroline

She has more UI when she has a bladder infection and she becomes more concerned that she might pee on her husband or wet the bed.

Clay

Her worst case scenario and the thing that would be the hardest to get over would begin with infection, so stinky, smelly, cloudy and sediment filled urine, and then having UI while someone was giving her oral sex. As bad as it would be for her, it would be 10 times worse for the guy. It is one thing to be peed on during sex which she does not think is that bad, probably because she has done it so many times, but she thinks that it would be traumatic to pee in someone's face, and especially if she had an infection.

Brooke

She worries about leaking during sex if she has a bladder infection because the urine is darker, cloudy and would have an odour, and that has the potential to be really embarrassing.

4. Preparation and precautions for urinary incontinence

There are a number of actions the women take to prepare in the event that UI should happen including wearing a pad or a diaper which can be embarrassing, as well as laying down a “pee pad,” or a mat, on top of the sheets which takes away from the moment. The women talk about the importance of being prepared and the importance of the supplies they use. The main precaution these women take in an attempt to avoid UI during sex is to catheterize prior to engaging in sexual activities to ensure that the bladder is empty. Though this can be an effective method for preventing UI, catheterizing before sex can be detrimental to the sexual experience. Foreplay may have to be put on hold while she leaves to catheterize which disrupts both the mood and the momentum, and the women feel like they have to start all over. One woman shared a very personal story and told the researcher of a specific time when leaving a sexual situation to catheterize ruined the ‘threesome’ she was planning to have, and because it ended so horribly, she would never try this type of sexual activity again. She concluded by saying that if she had not had to leave to catheterize, it could have turned out very differently and it could have been a good experience. Another woman said that catheterizing affects her sexual life for the reason that her husband will no longer initiate sexual activities because he believes

that she will just have to leave to catheterize anyway. An interesting point that multiple women discussed was that when they catheterize prior to engaging in sexual activity and have sex with an empty bladder, they have less sensation and are unable to feel as much sexually. Often times, sensation is decreased after SCI, and though catheterization was the number one method these women used to prevent UI, it seems to further decrease any remaining sensation that they may have.

Supporting Quotes:

Mary Cat

Her precautions for UI are wearing the most absorbent pads and buying disposable pads to cover the bed when she travels, as well as watching what she drinks.

Caroline

She would be prepared in the event that UI were to occur by wearing a pad, but sometimes she would leak through. Before having sex, she goes to the washroom to catheterize and empty her bladder to avoid UI. This affects the spontaneity and mood of sex by stopping the momentum.

Clay

She used to wear pads and adult diapers in case she experienced leakage from her bladder. Prior to engaging in sexual activities she always lays down her “pee pad” as part of the “getting ready part.” She says that doing it takes away from the passion, romance and heat of the moment when she says “just wait a second while I put the pee pad down.” She will always catheterize before sex though she wonders why because she will still be incontinent anyway. She will pee, then they will play, then she will pee again, so there will be two pees before the actual penetration part, and if she has to leave to go pee while they are being intimate, they will have to start all over again.

Sarah

She says that she sticks to certain types of beverages because what she drinks affects her bladder. For her, the main contributors to an overactive bladder are alcohol and caffeine. She tries to go to catheterize before she has sex, but she thinks that she is able to feel more sexually when her bladder is full. Sometimes they have to stop in the middle of sex so she can empty her bladder.

Brooke

She carries a blanket in her bag of supplies that she lays down during sex and can take with her if she is incontinent. When guys comment on her level of preparedness, she tells them that things work differently for her, and when her friends invite her places they do not think ahead of time like she does. Emptying her bladder before sex is the main thing she does to avoid UI during sexual activity. Even after her bladder Botox, she still

continues to go to the washroom beforehand out of habit to avoid UI. However, when her bladder is empty, she does not feel as much sexually.

Jessica

She always watches what she drinks, and how much she drinks to reduce the likelihood of experiencing UI. She also wears diapers all the time which she says is “embarrassing.” She has not been sexually active since her injury but if she were to participate in sexual activities, she says that the only precaution she would take to avoid UI would be to catheterize prior to having sex.

Tina

She wears a pad when she is out so if she leaks it is okay until she gets home. Her commode is a very important thing in her life that she cannot be without, and anywhere she goes, she needs to have it. To prevent being incontinent during sex she will catheterize before being intimate, and she will catheterize again afterward to prevent bladder infections which increase UI.

5. Partner’s reaction determines her feelings toward the phenomenon

Having an understanding partner is very important. The reaction of the woman’s partner regarding the phenomenon affects her desire to either have a sexual relationship, or to refrain from intimacy. The more positive reactions she receives, the more positive her feelings are toward the phenomenon, and the more open she becomes to sexual situations. If the woman had been receiving negative comments and reactions from potential and/or actual sexual partners regarding the phenomenon, she would most likely be less open to partaking in sexual relationships. Though the women appreciate someone who is understanding of their situation and a supportive partner makes it easier to deal with, having someone say that UI is okay still does not make it okay.

Supporting Quotes:

Caroline

Her husband never made her feel stupid about it when she was incontinent during sex so she was able to get over it.

Clay

She says that wanting to have sex has a lot to do with your partner’s reaction, and if he was understanding it would be better than if his response was “Oh God!” She goes on to

say that “having someone say that it (UI) is okay is comforting, but it doesn’t really make it okay.”

Sarah

Urinary incontinence did not stop her from participating in sexual activities because her boyfriend accepts her without judgement, but she does not want him to accept it. He makes her feel okay about it, and that bothers her because it is not okay. She does not want to pee on her boyfriend whether he says it is okay or not.

Brooke

She is more open to explain UI and sexuality because she has never had anyone respond by saying “eww, gross.”

6. Effects of urinary incontinence on sexuality

All of the women are all concerned about bladder issues when they think about participating in sexual activities. Three major themes evolved here. The first theme, *fear*, was identified by the use of words and phrases such as “afraid,” “worried,” “paranoid,” “scary,” “greatest fear,” “anxiety” and “panic attack.” The second theme, *embarrassment*, was characterized by the use of words and phrases such as “idiot,” “beyond embarrassing,” “not acceptable,” “ashamed” and “crawl into a ball and hide.” The third theme, *unpleasant*, was uncovered by the use of words and phrases including “disgusting,” “uncomfortable,” “not sexual,” “gross,” “undesirable” and “not pleasurable.” The women said that UI takes away from the joy of the experience, and if the negative emotions listed above arise too often, it could be enough to make someone withdraw from sex completely. In fact, two of the women interviewed said that they will not participate in sexual activities because of the possibility of UI. Another woman who does participate in sexual activities said that UI delayed her from having sex after her injury, and that if it were not for UI, she would have had sex a lot sooner. This woman also said that just her fear of UI, and not even UI itself, caused her to have panic attacks.

The women are not just dealing with their partners' reactions, but with their own feelings toward the phenomenon as well.

Supporting Quotes:

Mary Cat

She was afraid that she would be incontinent if she had sex, and her fear of UI “killed (her) sexuality.” Being incontinent during sex is not something that she is willing to compromise on, so going down that road is not even a thought. For her, UI is “beyond embarrassing” and it is “disgusting” so she does not want to experience it during sex because it would take away from the joy of the experience. She would be uncomfortable having a sexual relationship knowing that she would be incontinent, and even meeting Prince Charming would not change her mind because it is just not acceptable. Even if the person was very understanding, it would not make a difference because she still has to deal with her thoughts, and she is not in a good place about her bladder.

Caroline

She was afraid that she would “pee or poo” during sex. She was always worried and paranoid about “bathroom things” such as bladder, bowels and gas going wrong during sex because she would find it totally embarrassing if anything happened. The times she has been incontinent during sex have been embarrassing, and UI is still a little bit scary.

Clay

There was a time when UI was her greatest fear. After her first SCI she was guaranteed to pee during sex even if she had just gone to the washroom. Her bladder made her feel “not sexual,” but “scary, gross, undesirable and ashamed.” Because of the UI, she refrained from sexual activities and says that she probably would have had sex a lot sooner after her injury if UI was not an issue. Urinary incontinence stopped her from having sex when the moment was otherwise right, and delayed her from having sex altogether. Just the fear of knowing that UI could happen, and not even that it actually did happen, was enough to make her heart race and make it so that sex was no longer enjoyable. It went from being something that was enjoyable, de-stressing, relaxing and euphoric to something that could cause anxiety or a panic attack, and that is the opposite of how she thinks sex should be. She says she was “sweating and not because it felt good, it was because (she) wasn’t feeling good.” She says it is really sad when you are having sex and it is fear and worry that you feel. If that happens too often, you withdraw and do not want to have sex. She was initially set up with a leg bag, but says that she probably would never have gotten into bed with a guy with a bag of urine attached to her leg.

Sarah

The first time she peed on her boyfriend during sex “sucked.” She was so ashamed and embarrassed because no one wants to pee on their partner. She wanted to crawl into a ball, hide and never see him again because she felt like an “idiot” for peeing on him. She does not think that anyone should be peed on because it is not pleasurable. She says that it is embarrassing for both her and her partner.

Brooke

If she is incontinent during sex, she is embarrassed and worries about being able to face the guy the next day.

Jessica

She is sure that her bladder would definitely leak if she were to participate in sexual activities and that concerns her because it would be embarrassing. As a result, sexuality is at the bottom of her list and she is not sure that she even wants a sex life. Urinary incontinence is the main reason that she will not have sex.

7. A possible connection between pleasurable sexual sensations and urinary incontinence

The women in this study have revealed a connection between pleasurable sexual sensations and UI. The most common association that the women talked about was the potential connection between orgasm and UI. They disclosed that it can be difficult to tell the difference between the sensations that are felt during orgasm, versus the sensations that are felt while voiding. Consequently, the women begin to worry about UI when sexual activities are feeling exceptionally good, and this worry takes away from the enjoyment of the experience. As a result of this connection, the women have been anxious to do what feels good sexually, and despite being pleasurable, they have avoided several types of sexual activities altogether because they may lead to UI despite the fact that they would be pleasurable.

Supporting Quotes:

Caroline

At the beginning, she did not want to do anything sexual that was “outside the box.” She considered those things to be “scary” because they could trigger UI. When she is receiving oral sex, she is afraid that she will have a bladder spasm and pee in his face which she says “isn’t hot.” She has been afraid to do things that feel good because she feared that they would lead to UI, and that has stopped her from enjoying sex as much as she should.

Clay

Her sensation is very muted so it is sometimes difficult to distinguish between stimuli. She once peed at the same time she was having an orgasm and she was unsure if it was the peeing that had caused the orgasm. After that, she would sneak her hand down during

sex when it started to feel really good to see if she was peeing. That took away from the moment because she was worrying about what was really happening. At this time, she thought there was a connection between UI and orgasm. She gave UI so much power that she could have great sex, but if it ended in UI it would take away all the good and become a horrible experience.

Sarah

Sometimes she is unsure if she is experiencing an orgasm or peeing because they can feel the same for her. As a result, she is concerned about UI when the sex is feeling good. She will stop during sex to check to see if she has voided and there is usually no wetness there even if it felt like she had peed so she tries to let go and enjoy the experience.

8. Disguising urinary incontinence as something else

Sometimes, the women will try to disguise UI in the hopes of being able to pass it off as something else so their partners never figure out what it really is. In one case, a woman congratulated her husband and told him to “look at what he did!” then said that he had given her a G-spot orgasm. Another woman in the study disguised her UI as sweat. It might be embarrassing to an able-bodied woman for her partner to think that she had sweat so profusely that it made the sheets wet, but for this woman with SCI, having her partner believe that it was sweat was less embarrassing than having him know the truth and that it was actually urine.

Supporting Quotes:

Caroline

The first time she was incontinent during sex with her husband, she told him it was a G-spot orgasm because she did not want him to know what it really was.

Brooke

Most guys do not notice the incontinence until after they have finished having sex, and sometimes they cannot figure out what the wetness is. Sometimes they ask if it is sweat and she will say that it is so they think it is something other than urine.

9. Disclosure

Having a discussion with a new sexual partner about the possibility of UI during sexual activity has been described as “awkward” and “terrifying” by these women, but

for six of the seven women interviewed, it was still an important conversation to have. The women were not unanimous with regards to the timing that UI and sexual function information should be shared with a new sexual partner. Most of the women felt that it was necessary for this disclosure of information to occur before being intimate as it would allow the relationship to evolve, it would save her the embarrassment of having to explain what was happening in the moment, and it would reduce the chance that she would have a partner who would not be accepting of any embarrassing issues that may arise in that very intimate setting when she is most vulnerable. However, not all the women agreed that it was essential to share this information before having sex. One woman compared this sharing of information to a different situation by saying “It would be the same for an able-bodied girl who’s first thing out of her mouth to a new guy wouldn’t be that she had a previous abortion, and she would maybe tell him later on.” She said that she “wasn’t about to share very private things with a new guy I’m hooking up with for the first time.” The women did agree that the appropriate timing for having this discussion with a new sexual partner was not a science, but that they would tell him whenever they felt comfortable with him. The one woman who did not feel that this was an important conversation said that it would not even occur to her to discuss these things with her husband as sex is not a consideration at this point due to the UI she experiences. She is the informant with the shortest duration of time post-injury, and it is possible that she has not yet reached a point where she is ready to consider participating in sexual activities. In time, she may feel more comfortable and adjusted to life with SCI and her urologic management program may have had further improvements. At that point, she may become more open to re-developing her sexual identity.

Supporting Quotes:

Mary Cat

The amount of disclosure she would give to a new sexual partner regarding UI would depend on the person and the connection between them. She would need to be comfortable with him because nothing sexual would happen until that point. She would rather have things out in the open and would tell him about everything before becoming intimate, but the ground work would have to be there first and if that bond was not there, she would not be “so generous with (her) affects.”

Caroline

She would give zero disclosure about UI to a new sexual partner because she wanted him to think of her as a sexual person. She did not want the thing on his mind to be worry, wondering if she was going to pee on him. She might be worrying about it, but she did not want him worrying about it. She would wait to tell him about UI until they were in a serious and comfortable relationship because she was not going to share very private information with a guy she was just “hooking up with for the first time.” She would not necessarily share this information before being intimate, just whenever she was comfortable. It was over a year before her husband knew what was going on and how everything worked.

Clay

Sharing information about UI with a new sexual partner is based on intuition, it is not a science. She will share the information using jokes and then follow up by saying that it “wasn’t really a joke,” and she will tell them bit by bit. It is human nature to be inquisitive, so if she said something it would usually prompt the guy to ask questions and that would determine what she shared. Having that conversation “sucked” and was “very awkward.” It made her feel nauseous and nervous, and would make her heart race but it had to happen for the relationship to evolve.

Sarah

Her boyfriend knew everything that was going on right from the very beginning. There was no hiding it because as soon as you see her home, you are able to put things together. Having those conversations about bladder and sex was a little bit awkward, but she could talk to her boyfriend about anything and that is why she wanted to be with him.

Brooke

Because guys are either thinking about, or going to be thinking about sexual function, she covers topics such as catheterizing, toileting and how her body works right away. She tells the guy sooner if it is just sex, and later if it is a more serious relationship, but either way she tells him before being intimate. She would tell him as much as he wanted to know and would keep “spilling the beans” right from the beginning as long as he wanted to learn. Explaining these things is terrifying and these conversations “just sucked,” but she had to have them to out of respect, and to get what she wanted. She would want to know if the situation was reversed and she would be understanding, but she knows that not everyone is as understanding as she is.

Tina

She told her husband about her bladder related issues right after the injury and he is aware of everything bladder related.

Contrasting Quote:Jessica

It would not occur to her to disclose information about the possibility of UI during sex to her husband, or to even have sex with her husband because of UI.

10. Fear of Rejection

The women know how their bodies used to function and what sex was like before their injury. Knowing this, they worry that their partners post-injury will not be satisfied with their relationship together, and that they will no longer want to be intimate once they know how things work. They have a number of concerns in this area, but at the heart of them all is rejection. They have either experienced a man no longer wanting to be with them because of their SCI and its resulting consequences, or they are worried that if they are with someone, he will not want to continue to be with her once he becomes aware of everything that is involved. One of the women said that “you scare off all the men” who cannot handle everything that comes with having a SCI and being in a wheelchair. The women also no longer feel confident enough to approach men because they fear being turned down in the event that the man they chose to pursue is not interested in being with someone in a wheelchair.

Supporting Quotes:Caroline

She once soaked a guy while they were fooling around and she does not think that she ever saw him again. She says that “you scare away all the guys that can’t handle it”.

Clay

It would have been nothing for her to approach a hot guy before the injury, but now she waits for guys to come to her. She says this is effective and works as a “safety net” because it ensures that she will not be going after guys who would not be caught dead with someone in a chair.

Clay

All the changes to sex as a result of body, mobility and bladder issues affects the experience and she worries about the person she is doing it with wanting to do it again. Having conversations about UI with a new partner would make her nervous because she did not know how the guy was going to react. It was a huge risk to tell him, but a necessary one because he may be uncomfortable and not want to go any further, or even worse, he might say he that is okay with it and then in the moment when it actually happens, he could be so wrong about being able to tolerate it which would make her feel even more shameful because he is now disgusted. It is a necessary conversation to avoid those situations unless you can take the hurt, pain and anguish that come with being rejected. She would rather make the effort to avoid feeling that way. It is one thing to have that conversation face to face, and it is another to do it butt naked. It is easier to take rejection when you are fully clothed and in a less intimate setting.

Brooke

Her biggest concern and biggest fear about UI is being rejected and that the guy would not want to do anything intimate with her because of it.

Tina

She worried that if she was accidentally incontinent during sex, her husband would no longer want to be intimate with her. Sometimes she wants to catheter but her husband does not want her to. She thinks this is because if he saw the catheter, he might think it was unattractive and it might stop him from wanting to be intimate with her.

Chapter 5- Discussion

Five additional topics emerged that were discussed throughout the interviewing process and warrant mention. Though each of these five topics is related to sexuality and/or UI, that is not their primary focus. Therefore, they are being discussed separately in the discussion section of this paper.

1. Body Image:

The women all said that their bodies have changed since their SCI, and as a result, they do not feel the same way about themselves as they did before. These particular women seemed to have pre-injury levels of body-esteem that would exceed the general population. Kreuter and colleagues' (2008) made the conclusion that the women in their study with SCI rated their pre-injury levels of sexual satisfaction to be higher than that of the able-bodied controls due to a memory bias or glorification of their sexual lives prior to injury. Body image may operate on the same premises, and the women in the current study may have regarded their pre-injury appearance so highly due to the glorification of their bodies at a time before SCI. The women also said that they had never realized how important looks were until they were "different." Being unable to exercise or be active in the same way they had been prior to injury has resulted in weight gain, a loss of muscle tone and an increase in how "jiggly" things are. They have become concerned about the "bloated belly look" that they now have due to a lack of muscles in the stomach, and they have become concerned about the sagginess and decreased size of their breasts as a result of being hunched over, losing muscle and wheeling in their chair. These body changes were described as "not sexy" and because their bodies have changed, the women did not feel as sexual as they did prior to SCI. The women were never asked to talk about the

clothes that they wear, yet six of the seven women brought this up as an issue. They cannot wear the same clothes that they used to because they no longer look good on their bodies, and they have made adjustments to their wardrobe that has allowed them to hide their body and their leg bag. They have been affected by society as there are certain expectations and a presupposed standard of beauty that they no longer fit. One informant said that she no longer feels that she possesses the qualities that she would use to define what “sexually attractive” means. Body image post-injury is directly related to sexuality, and as one of the women said “my sexuality has been affected because I now lack confidence and self-esteem (due to issues with body image)” and those issues have been a major cause of her depression. Another woman revealed that she wishes her boyfriend could experience the best of her, but that he just has the “leftover” her.

Quotes:

Mary Cat- Before the accident she was happy with the shape of her body because she was young, thin and tall. She liked fashion and clothes, and it was important to her husband that she had a ‘perfect body.’ She is no longer happy with her body and says that she is “disgusted” by it. She feels this way because she gained a lot of weight after the accident since she was unable to exercise the way she normally would have. She does not feel as sexual as she did when she had a nicer body.

Caroline- Right after her injury, the societal obsession with ideal bodies was a big problem for her. She was 5’9”, 125 pounds and she had always received a lot of attention, but after her injury, she suddenly had a very different body. In the beginning, she had been shy about all of her scars but she is no longer shy about them with her husband. She says that because of her high level of injury she has no stomach muscles, and her main concern is her stomach. She says that it sticks out and no matter how much she works out or how much weight she loses, she cannot do anything about it because there is nothing (no muscle) to hold it in. She was also concerned and very self-conscious about her breasts as they became “smaller and saggier” because of her lack of chest muscle. She had a breast augmentation surgery which helped her self-confidence and now can sit topless during sex. She says that she was always a vain person and that she was obsessed with her appearance. Her husband thinks that she is still vain, and he says that she works out like a maniac. She says “it’s hard not fitting into the perfect little picture of what people think an attractive person looks like, and even if people think I look great, I’m still self-conscious even if I seem confident because I don’t feel as hot as I used to.”

Sarah- In her opinion, the societal obsession with ideal bodies “sucks.” She says “not to brag, but I had the kind of body everyone wanted with an ass and boobs, so I didn’t care about society because I was the girl that every guy wanted so I didn’t pay attention.” She says that she even had girls “hit on her constantly,” but her body is different now because of the SCI. She was initially working out five days a week, four to five hours a day because she was trying to walk again, but it became her whole life and she was still not anywhere near being able to walk so she stopped working out and gained a lot of weight. She calls her body “gooey” and she says that it is not sexy. Her breasts have gotten “larger and saggy which also isn’t sexy.” She has a little bit of muscle, but it is “mostly flabby” and she does not like being naked in front of her boyfriend because things are more “jiggly than they are hard” and she does not think that that is right. She used to take showers with her boyfriend, but since the accident it is awkward because she is wondering how her ass looks, and how it feels in his hands. She hates her stomach and breasts because they sag more than normal because she is hunched over. When she goes out she uses a leg bag which limits what she can wear. She says that she cannot wear “fuzzy boots and tight pants or mini-skirts with the bag, and guys like the girls with the fuzzy boots.” She will never wear a bikini or a dress because of the “bloated belly look” she gets from not having stomach muscles. The clothes are a part of her not feeling as pretty as everyone else, and for that reason as well as not having the body that she used to, she does not go out as much, especially in the summer. This is not who she was before and it affects her body-esteem, sexual-esteem and confidence because she does not feel “totally sexy anymore.” She wishes that her boyfriend could experience her before, and not “all messed up” because she thinks that he deserves “the best girl, and I can’t give him the best of me that I used to be. He just has the left over me.”

Clay- Prior to SCI, she thought that she had “nice legs, a tight butt and moves on the dance floor,” and she considered herself to be very sexual. She says that she was quite successful at attracting men before but feels differently about it now because when she looks in the mirror, she does not see all the qualities that she would use to define what ‘sexually attractive’ means. She says that sadly, she subscribes to society’s obsession with ideal bodies. When she sees clothes in the store she thinks that they were made for someone who stands and notices all the places they will not fit her. She says “it gets to me because I aspire to have a beautiful body with minimal blub, and culture has power like that.” She would be more confident if she saw people in wheel-chairs modelling. The main body issues that concern her are a lack of muscle and body shape. Things “jiggle” because she does not have the muscle tone, and she thinks that her stomach is large. She says “it’s easy to think looks don’t matter when you’re beautiful.” She used to be healthy and fit so it was easy for her to think it was all vanity, but when she was “different” she saw herself as “disgusting,” and she did not realize how much it meant to her to be beautiful.

Brooke- Her current attitude toward sexuality is affected by her lack of confidence and self-esteem. She used to like showing off her body, and she was open to doing so because she thought that she was in good shape, and that she was attractive. She was not afraid to get down to her underwear, but that has changed since the accident. She used to be

athletic with strong, muscular legs, but her legs have now atrophied. She misses her “abs and awesome stomach,” and says that because she is paralyzed from the chest down, there is no muscle to hold her organs in against gravity so she feels like she has a “gut.” People tell her that she is crazy, but her stomach is all that she sees when she looks down. This has affected her eating habits to the point where people have said that she was too thin. She agrees that they were probably right, but says that she was trying to lose weight in her stomach because she is very conscious about it. She thinks that society loves a big chest and she used to be very proud of hers, but because of wheeling in her chair and losing weight she has gone down a cup size. There is “less chest and more stomach” so she tries to accentuate her chest by wearing bras that make her look two cup sizes bigger, and to reduce her stomach by wearing Spanx that hold everything in. She has had to re-do her wardrobe because things that used to look good on her no longer do, and it bothers her that she cannot look at her butt in jeans. She used to love to shop, but she says that certain clothes would look better if she was standing, so she will skip over it. In her field of education she has learned that you should be comfortable in your own skin. She knows curvy ladies who are comfortable, but she is not comfortable in the chair.

Jessica- She has gained 40 pounds since her injury. She has never weighed this much, not even when she was pregnant, and she hates it. She says that she feels “blah,” that she has no muscle tone left and that she does not feel good about her body. She used to be quite active and exercised three times a day, and walked her dog for an hour. She is no longer able to do those things because of the SCI and she misses them. According to her, that is the reason for the majority of her weight gain, though a small percentage may be accounted for by aging. Society has affected her because “it engrains in our heads that you have to be thin and perfect and that’s what you see on t.v., and in magazines and fashion.” She says that even though she is getting older and will be 60 years old this year, she is still affected by society. She dresses differently and is less fashionable because of the weight gain and because she does not feel comfortable with her appearance. It bothers her when she looks at clothes that she used to be able to wear that she cannot wear now. She would have never been caught dead wearing track pants outside the home before her injury, but that has changed.

Tina- She gets jealous of other women when she cannot wear what she wants to wear because her body is different now that it was before her injury, and that has been very hard for her. She exercises in the Neuromuscular Skills Acquisition Lab at Brock University, and she does not think that there is anything more she can about it. Everything is different about her body. It has changed, and because of that she does not feel the same way about herself that she used to.

2. Information (sources and timing):

A major issue that was uncovered during the interviews was the shortage of information that is available to women regarding sexual function after SCI, and this deficiency of information has been noted in a number of other research papers

(Benevento & Sipski, 2002; Ford & Orfirer, 1967; Pentland et al., 2002, & Singh & Sharma, 2005). The women were highly disappointed with the lack of information they received while they were in rehabilitation, and they were disappointed with how little information was provided to them even after they requested it from nurses and Doctors. One of the very few resources that were provided in rehabilitation was a sex information video, but after hearing the sort of impact that it had on the women, it appears as though the video did more harm than good. The women took matters into their own hands and found peer mentors through the Canadian Paraplegic Association, talked with friends who were in the same situation and compared experiences, experimented and looked up information on the internet. Though these approaches have been somewhat effective, the women expressed that it may be difficult for introverted individuals to talk about this very personal topic with other people, and that it takes someone who is “very open” to be willing to experiment sexually without first having information. They also had issues with the information that was found on the internet not being trustworthy or reliable, and said that it was predominantly focused on male sexual function. They said that it would be difficult to create a book that would be capable of answering every question and concern regarding sexual function because every woman’s injury is different, and every woman’s body responds uniquely. They highly recommend continuing and expanding the peer support program. They suggested that pictures would be more helpful than text, and said that information should be less technical. One of the women had a friend with a PhD in sexology, and proposed that it would be helpful to have someone with her expertise available to use as a resource. Some of the women did not care who this information was coming from as long as it was out there to get, but other women felt that the information

would be more valuable, and that they would be more comfortable if it was coming from someone who was also female and/or also had a SCI. The majority of the women felt that this information should be provided immediately after injury to ease their minds and give them hope for the future. However, they said that this information would need to be provided again when they are back in the community and are ready to apply it. One woman said that she had not bothered to look for this information because “it is what it is, and no amount of information will make things the way they were before.” Many of the women are more than willing to be there for other young women who are in the same position as they are. They are a “wealth of knowledge” and want to be used as a resource to help others. The main point here is that the women are frustrated with the lack of information and resources that are available regarding sexual function after SCI. They wish and hope that there were more sources out there to assist them.

Quotes:

Mary Cat- She has not found a lot of resources on sexuality or UI, and in over 30 years of living with a SCI, she has never had any help with sexual function. She has not been given any information regarding sexuality, but she is resourceful on her laptop and uses chat lines and websites to compare her experiences to the experiences of other women with SCI. She has always been hands on about her situation and uses her limited nursing training to understand the medical terms she reads online. The information she has found online is gender neutral and she says this is because medicine does not take gender, however she thinks that if she looked into it with more depth it might become more gender specific. She is not happy with the resources in the Niagara Region, and says that she has gone in circles looking for information and going to specialists. She says she might be looking in the wrong places but she is frustrated with her inability to find information because even though she keeps looking, she cannot seem to get anywhere. She has been really frustrated with both locating people who can help her, as well as the lack of knowledge these people have when she finds them. She tells the researcher that people are saying the information regarding SCI is moving forward and that things are getting better, but she does not see it. She is sure that the amount information is increasing, but she does not find this to be the case in the Niagara Region. She wishes she had the resources to connect with someone who could tell her where she is going with her disability. She has questions about her bones, her spine, her bladder, and if her head might fall off and she just wants someone to answer them. She is butting her head against

the wall because the information is just not out there. She got some information about UI from her urologist and according to her, the best time to get information about bladder function would be right away so you are able to get on top of it. She does not care who she gets this information from about sexual function or UI because she does not get embarrassed anymore.

Caroline- When she was in the hospital, she asked about sex and the nurse told her that sex was not important and that she should be focusing on other things. She did not ask about sex again for a long time after that incident. She had some other nurses who listened, but they did not have a lot to share. In rehabilitation, she watched “a lame video where a girl couldn’t feel a guy’s touch and told him to touch her somewhere else.” She said it was “so stupid.” She ended up doing her own research by talking with a woman who had a SCI through the peer support program which she says was a great resource, but she acknowledges that some newly injured people may be afraid to ask a peer support worker these types of questions. She was not afraid to explore and said that “you learn, just as an able-bodied person, what feels good and what doesn’t, what you can feel and what would cause a problem. It was a learning process.” She got a book from the Canadian Paraplegic Association that had a chapter on sex, but she found learning from other people’s experiences was more helpful than learning which part of the spinal cord affected which part of her body. It is her opinion that there could be more information on everything. Her friend just finished a PhD in sexuality and she thinks that it would be good to have someone like her in a rehabilitation setting who could answer the “billion questions that newly injured people have.” She thinks that it would be nice to have more information available specifically on the psychological side of being a woman with SCI and how that affects sexuality. She says there are more resources out there on UI than sexuality, and the information available about UI is for both men and women, though she thinks both sexuality and UI information is easier for a man because “his equipment is all out there.” She thinks the ideal timing to receive information regarding UI would be early on after the injury. As for the timing of information regarding sexual function, she says that some people were having sex in rehabilitation so sex information should be given whenever the person is ready for it and that timing could vary. A lot of the information she got in rehabilitation focused on keeping her alive, but having information available about sexual function and knowing where to get it would be nice. She wishes there were more resources out there, especially for young people, but says that even as an older married person, if she were to get injured now, she would want to know. She suggests that a resource that is not a manual would be great, like a group of people and a place where they could turn for answers. She would love to be a part of something like that because it would be wonderful to help people so they are “not floating around for years not knowing, or being afraid to get out there.”

Sarah- She is only aware of a few educational resources and says that are not a lot of resources out there, but she understands because there are not a lot of people in her situation. The reason she agreed to participate in this study was so that there could be more information out there for young people who get themselves into this situation, and she will help in any way she can. She has not tried to look for information about sexuality because “it sucks and I’ve just accepted it. I would like to do something about it and

be who I was before and feel everything, but I don't think that anything can change me." She knows there is some information out there because she gets e-mails about various books and web sites, but she has not bothered to look at them. In rehabilitation everyone got a book of information on everything SCI related, and that included a chapter on sexuality, but she did not read the book because she wanted to experience it for herself. Her friends help because they discuss things and they figure that if they are both going through it, it must be normal. She also uses the internet as a tool. She would not care if the information came from a male or a female, a person who had a SCI or an able-bodied person; she just wants the information to be available at an everyday store. She is not a "judgy person" and she says that research takes a lot of time and effort so she does not care who does it. She also says that "you can be knowledgeable about something even if you are not in a wheelchair." She thinks that it would be ideal to get information about UI and sexuality right away, and says that an individual with SCI should definitely acquire as much information at the beginning when he or she is in rehabilitation as one can. She makes this suggestion because she says that there is not a lot to do in rehabilitation and that when you leave, you feel lost, and if you have questions you feel like there is no one to ask. She says the main factor for determining the timing of receiving information is that the person has to be accepting of it. She says that "every case of SCI is different so there can't be one book for everyone since everyone feels things differently." She suggests that the use of a picture book would be better than a novel because a novel would be "boring." She says that a video would be awkward and cheesy, and compared it to a *Body Break* commercial that is "old school." She would not want to watch it, and if she did, she would think it was stupid and would not remember anything from it.

Clay- She says that you learn about UI because it is a daily thing and that she has gotten a lot of information about UI, but very little as it relates to sexuality. She has received no information on sexual function at all. She says that the internet is a "big tool that can educate people about these topics." It blew her mind, and she says there is more than you would ever want to know on the internet. She has a very sexual friend who also has a SCI and who uses pornography available on the internet that shows people in wheelchairs in it as a resource. The Canadian Paraplegic Association is another resource, but it can also be found on the internet, and there would probably be something at the library, but no one goes there anymore. She says that the Canadian Paraplegic Association puts on education sessions, some of which are on sexuality, though they would not go as specific as 'female sexuality.' She attend one of the workshops, but it was all about how to get erect and there was very little on lubrication, and no talk on positions which she thinks should have been a key part. She did not pay close attention because it was irrelevant to her. She thinks that sexual function information is more geared towards men because erectile dysfunction is a bigger issue in society than lubrication. She is open and does not mind talking about sex, and thinks that it is valuable to have men and women talk about it together, but she knows that most people probably would not feel the same way. The information that she has regarding sexuality has come from talking with friends and experimenting, but the biggest way that she has learned has been through trial and error. She has always liked taking risks so that made her comfortable to try things without having knowledge, but she understands that other people might want to prepare. She suggests that shy people should learn from having conversations with people who are

doing it which is why the Canadian Paraplegic Association's peer support program is valuable. When she gets information from able-bodied people she feels like it is not relevant, and says that it would be so much more appropriate if it came from someone in a wheelchair. She would prefer to get information from a female because she would be more trusting and find more value in it, though she would be curious and interested about what a male would have to say. Her initial response to the first bit of information she received regarding sexuality was wondering what she was doing there because no one would ever love her and that this opportunity would never present itself, and that maybe she never wanted it to. At the time, she was inpatient and there were a lot of things that had to happen before she was going to get naked in front of someone so she says that it was bad timing. She thinks that giving the people who are wondering about sexual function some information when they are in the hospital is not a bad idea so they know that other people are doing it, but she thinks that they need this information again when they are out in the community; once they have a place to live and a job, and are ready for some company. For her, sex was just a little bit lower on her list of priorities, and not because it was less important, but because she felt like she needed some other things first in order to be worthy and wanted by someone.

Brooke- She was disappointed when she was in rehabilitation because she did not learn anything about sexuality when she was there. They did provide a movie that she says was "from the 1970's and scarred me for life." Her initial response to that sex video was deep depression that that was what her life would be like. She watched two seconds of the video looking at the possible things she could do in a wheelchair, then fast forwarded it and broke down and cried. After that, she asked for more information on sex but they did not have any, and at the time of the accident it was crucial to know these things but nothing was available. She was really "sad" with the resources she had at the time, and says that they were inadequate. She thinks this is something that needs to be changed. She was so emotionally unstable at that time that she says any information, no matter who it came from would have been helpful. She says that everyone is different when it comes to sexual function and orgasm so she was unable to get any answers from the Doctors because they did not want to tell her something that might never happen. They did not even give her hope because it has not been scientifically worked out like walking, or having a baby. Her Doctor gave her some information about how to manage UI, but that was it. She says there was a lot of information for men about getting erections, but nothing for women about sexuality. Her peer mentor from the Canadian Paraplegic Association was one of the biggest influences in her sex life post-injury, and her peer mentor was the source from which she learned the most about sex. She thinks that she was very lucky to have her because without her, she would still be scared. Knowing that her peer mentor still had sex and that she still enjoyed it helped to ease her mind. She is now a peer mentor herself and says that she is a wealth of knowledge but has been disappointed because the Canadian Paraplegic Association has not contacted her to mentor anyone. She suggests this might be because "young women are just too shy to ask which is unfortunate." Her knowledge regarding sexual function has also come from experience. Her 'openness' helped her to be more sexually engaged and she cannot imagine what people who are less open than her go through. She does not mind experimenting, but she realizes that a lot of people are not open to experimenting or learning based on what other people say. The internet has been another resource, but she

does not find it reliable because as a student she has been trained to think critically. She looked up information about orgasm post-injury, but found nothing that was useful or verifiable, and says that the information she found was entirely targeted toward men. She says there is a good network on Facebook where everyone with SCI wants to be friends and she talked with a girl from the United States who was similar in looks and age about various topics, including sexuality. She thinks the timing for getting information depends on the person and how important sex is to them. It was important to her almost immediately and it was hard because it took her so long to find out about sex, but she knows that sex is not that important to everyone. Being in a chair with different functional abilities makes it harder to compare and less understood, and what works for one person might not work for another. She felt that other people with SCI were the only ones who could answer her questions.

Jessica- She did not see any information on UI or sexuality. Her physiotherapist told her she should talk to an incontinence nurse, but other than that, no one told her anything about UI or sexuality, nor has she heard of anyone else receiving information on these topics. She does not think that the amount of resources available is adequate. She thought that she would have received this information when she was in the hospital which she says would have been helpful. She says that her injury is new, but that it would have been nice to have that information from the beginning. She thinks it would be best to get this type of information from someone who was “definitely female” and preferably with a SCI.

Tina- She is not sure what resources are available to help with UI and/or sexuality. She tried looking on the internet, but she did not find anything. Her initial reaction to the first information she received about sex was fear because the Doctors warned her about AD. The information that she has seen has been for people with SCI in general, and not specifically for men or women. She was not told about sex, she had to ask for the information and she felt like she should have been given more. Since she had to ask for the information, it was specific to her and it came from a female nurse and a female Doctor. She says that she would not even ask a man about sex and that she would be most comfortable this getting information from someone like her (a female who has a SCI). She thinks that the best time to receive this information would be right away so that you know your life is not over and that you can still have sex.

3. Doctors:

The primary care Doctors of these women are not specialized in SCI and the women feel as though their Doctors are somewhat to not at all knowledgeable about SCI. They say that the best things their Doctors do are write prescriptions and realize their limitations then refer them to someone else. One woman’s Doctor went as far as to say that he no longer felt comfortable treating her after the injury and told her she should

switch Doctors. The women will teach their Doctors what they need to know about SCI in order to treat them, but because of their lack of knowledge, a number of the women avoid going to the Doctor unless it is absolutely necessary. One woman in particular has had a number of negative experiences with Doctors and now feels very strongly that Doctors are useless because they do not understand how her body works, nor do they understand her capabilities and limitations. The women have not discussed sexual function and/or UI with their Doctors at all except for one woman who's Doctor always asks if she is experiencing any problems sexually. The women have discussed UI with their urologists who they visit once every two years.

Quotes:

Mary Cat- She has never discussed sexual function or UI with her Doctor but she thinks that he is great and his biggest asset is that he refers her to a specialist. He is a sports Doctor, but she says that he is as good as its going to get in the Niagara Peninsula.

Caroline- She has never talked to a Doctor about sexual function, only fertility, because sex never came up. She does not think that a Doctor has ever asked her if she even has sex. She says the extent of her conversation with her General Practitioner is that "he writes my prescriptions for Ditropan," but she says that he is somewhat knowledgeable about SCI because she teaches him. She is his first patient with SCI and she says that he knows she knows more than he does and he is good because he knows his limitations. If she has a bladder infection, he will give her the prescription, then they will do the test and she does not have to wait like you do with other Doctors.

Sarah- Her Doctor is not a SCI Doctor so she does not go to him with many issues and only calls him when she needs a prescription signed. She thinks her Doctor would be open and willing to discuss UI and sex with her, but they have not had those discussions because she has not asked him too many questions.

Clay- She could go on and on about her frustrations with Doctors. Once when she was in pain the Doctor told her that she could not feel pain because of the nature of her injury. Another time, she told the Doctor she thought she had broken her pelvis and he told her she was just constipated. Three days later in the emergency room she found out she had multiple fractures. It was frustrating when she knew she had a bladder infection but the Doctor would not give her medication until she had tests done, and by that time, it was 10 times worse. She has never talked to her Doctor about sexuality, and in her opinion, Doctors are useless so she goes as little as possible. She says that when a Doctor does not

know what AD is, she has no respect for him or her because that is the world that she lives in. She says the tables in their offices are too high and she cannot get on them for her exam so they half ass it rather than help her up. Doctors have been surprised that she works and drives, and she says that the bottom line is that “they don’t know shit.” She believes that they still have the same mentality they had back in time when people in wheelchairs were institutionalized.

Brooke- Her family Doctor was an older man who had been treating their family for generations, but he had not had a SCI patient in 42 years and he was not comfortable caring for her. She switched General Practitioners to a younger man who works with her SCI specialist so they have great communication.

Jessica- She is unsure how knowledgeable and/or comfortable her Doctors are discussing UI and sexuality because she has not talked about it with them.

Tina- Her family Doctor is not a SCI Doctor, but she is experienced and they have a close Doctor-patient relationship. Her Doctor is comfortable discussing sex with her and always asks her about sex and if she is having any problems sexually. The Doctor also asks her husband about sex.

4. Spinal Cord Injury- Worse for a man or a woman in terms of sexuality?

One woman stated that the level of difficulty experienced with regards to sexual adjustments after SCI would depend on the person and their injury rather than gender, but the remainder of the women were unanimous in saying that it would be more sexually devastating for a man to have a SCI than it would be for a woman. The women felt this way for a number of reasons and acknowledged the difficulty and sometimes even the inability that a man may experience to become erect after SCI, as well as the embarrassment of a reflexive erection that he is unable to control. They recognized that decreases in strength and mobility after SCI would affect his ability to fulfil his societal role in a sexual relationship as the one in control, and that he would have to assume a more passive role. They believe that it is easier for a woman to be sexually satisfied after SCI because sex is more meaningful for a woman than it is for a man, and because there are multiple ways for a woman to experience sexual pleasure where as for a man, it is all

about the penis. They imagine that for a man erectile difficulty, not having the ability to be in sexual control and difficulty climaxing would have a negative effect on his feelings of manly-hood and masculinity, and may make him feel inadequate in terms of what society expects from a man sexually. The women did however feel that it would be easier for men in one respect as their female partners would be more understanding of their situation as opposed to women who would have male partners that would not be as understanding.

Quotes:

Mary cat- Adjustments would be harder for a male because getting erections isn't easy to do with a SCI, if at all, so being robbed of his manly-hood and dominance would be devastating for a man.

Caroline- Sexuality is more often affected in men after SCI and it can be harder for them in some senses psychologically because they feel like they should be dominant but they are suddenly in a more passive role. It's easier for the woman to be picked up and play the damsel in distress and still feel hot, but for a guy that could be embarrassing.

Clay- Sexual adjustments would be more difficult for a man because of their macho image and because they have the equipment necessary for sex. Women can be pleased in more ways because they have more erogenous zones, and because the psychological and emotional connections are more important. For a man it's mostly about the penis so erectile dysfunction is a huge problem. Men are luckier in the sense that their female partner is likely to be more understanding.

Sarah- A man's big ego about being a man, producing and taking control would be knocked down by SCI. Guys live through their wieners and if they can't get it up, they are going to feel pretty small. I know a lot of guys with SCI who can't get it up, and others who do it randomly and are embarrassed by it which isolates them and makes them want to crawl into a ball.

Brooke- I feel more sorry for a man after SCI because it is difficult to get an erection and be sexually satisfied. Societal values of manly-hood may also be affected. I pity men knowing they may never achieve what I have.

Tina- A woman would be more supportive of a man with SCI and a woman would understand and handle more.

5. Children:

For these women, their questions regarding the ability to become pregnant after SCI were answered right away so this was not a major and ongoing concern for them. Their main concerns with regard to children had to do with the potential health related complications of pregnancy and delivery, further decreases in mobility during pregnancy, and a concern about their ability to care for a child and to provide everything it needs due to their reduced energy and mobility, as well as psychological issues such as depression. The women who had been mothers before their injury felt frustrated when they were unable to do things with their children that they used to do, and when they were unable to help their children as much as they did before. One of these women chose to have her children to live with her ex-husband because she did not feel that she would be able to adequately care for herself and her children. The main concern of the women who became mothers post-injury was that one day their children would get angry at them for not being able to do all the things that other mothers do. Of the two women who did not have children, one had been unsure about being a mother before her injury and the other had wanted to have children in the future, but they have now both decided that it would be very unlikely that they would have children, or that they will definitely not be having children because of the issues that would be involved as a result of SCI. Almost all of the women who are mothers said that their children have grown up to be incredibly accepting of individuals with all sorts of disabilities and that they do not think their children would have learned to be that way if they had not had a SCI. Being a mother is seen as part of what it means to be a woman. If women with SCI are choosing not to have children because of the difficulties they may face as a result of SCI, it may affect the way they feel

about themselves as women which in turn, may have a negative effect on their sexuality and relationships.

Quotes:

Mary Cat- After the SCI she could barely look after herself so her ex-husband took their children who were five and seven years old at the time. It was hard not to be there for them and the SCI greatly affected her relationship with her children, but she did not have the energy to take care of all of them. After the accident, she could no longer handle everything so she chose to just take care of herself and everything was all about her. She does not think this was selfish because she says that “if you don’t take care of yourself, you’re no good to anyone else, and if you’re not a whole person, how much do you have to give to someone else?” She says that her children have grown up to be good people. They are kind, courteous human beings with values, and they are good with people who have disabilities. She does not think they would have grown up to be this way if it she had not had a SCI.

Caroline- At first after SCI she was unsure about getting pregnant because of the physical complications of the pregnancy itself, as well as the difficulty she would experience with raising a baby. She was unsure if she could even get pregnant, and if she could, she wondered if she would be able to raise it “properly” and give it everything it needed. She worried that she would be frustrated with her own limitations. She now has a three year old son and being pregnant was very challenging because she was on bed rest for six months and had severe low blood pressure. She does tons with her son, more than some of her able bodied friends do with their children, and she says she might be compensating for the SCI and spoiling him, but it is still frustrating when she wants to do things with him but is unable to. She was already injured when she had her son so he does not know any differently and probably thinks it is weird that other moms walk. She is just ‘mommy’ to him and she says things may have been different if she had him before the injury because he may ask why she does not do things with him she used to do. She says this is making him grow up to be very understanding of people with disabilities, knowing that people may not do things the same way you do, but that they still have so much to offer. She has lots of friends with disabilities and her son does not look at them any differently and she does not think he ever sees it.

Sarah- She says that her relationship with her daughter is different because of the SCI, and that is a huge tear in her heart. She says that she knew she was in a wheelchair before she became pregnant, so it is not fair to her daughter that she has to deal with it because it is not her fault. She is not sure if it was selfish to want to have a child of her own, to have somebody, when she could have stopped the pregnancy so her daughter would not have to deal with all these issues. She is not looking forward to the days when her daughter will yell at her that she hates her because she is in a chair and slows everyone down. It is a big worry for her that her daughter will leave her.

Clay- Before her injury, she was undecided if she would have children and said that all the circumstances would have to be right, and that it would have to be as a family unit. She looked into having children after SCI but when she researched it, it did not appeal to her. She is an active person and would not have been able to weight bear or transfer, and she would have been on bed rest for the last months of the pregnancy. There was the possibility that numerous complications may occur during the pregnancy, and she did not want to imagine, as a person with SCI, how difficult it would be to take care of a child and all the equipment that would be involved. She had been leaning toward not having children before her injury, and all those things turned her right off so the SCI just finished off the con list.

Brooke- Since the accident, she is not sure if she wants to have children. This is not because she cannot have children, but because she is worried that she would not be able to take care of kids and that she would not have enough energy to do so. Before the injury if she accidentally got pregnant she knew she would have been able to handle it, but now she does not think that she could, especially with her emotional issues (depression, mood swings, post traumatic stress disorder) and lowered energy levels. She knew that having a baby would have been hard work before, but now with all these issues she does not even want to go there unless it was the perfect guy and the perfect time. She does not see a baby in her future as much as she did before, and that sometimes affects her depending on the day. When she wasn't sure if she could have a baby or not it was another huge aspect of her life that had been taken away and it made her feel worthless.

Jessica- Her relationship with her sons has changed because she cannot help them the way she used to.

Tina- Her relationship with her children is good and she says that it is the same as it was before the injury, but she feels really bad when her kids ask her when she is going to walk again and why she does not drive them places, or sleep with them anymore. There are a lot of things that she wants to do with her kids like swimming, playing at the park, and doing things for them that she can no longer do and she says that she "can't do too much."

Sexual Frequency

It has been accepted that the frequency of a woman's participation in sexual activity decreases after SCI. Of interest in this particular study was the finding that not all women experienced that same decrease, and there was a broad range of responses with regards to the frequency of participation in sexual activity. The women sat on both ends of the spectrum, some stating that they abstain from sexual activities altogether, some stating that they have "a whole lot of sex," and others who stood somewhere in the

middle. These findings could be a result of the exploratory nature of this investigation and the heterogeneous sample that informed the results.

Quality of Life

It is evident that SCI and its resulting consequences affect QOL in numerous ways. Changes to appearance and physical function will often negatively affect self-esteem and sexual-esteem, and will also negatively affect sexual function and sexual satisfaction, all of which would have adverse effects on QOL. Difficulty initiating and maintaining relationships, as well as the role changes that occur within relationships after SCI would also negatively affect QOL. The anxiety associated with UI as a result of SCI, the stress involved with the planning and preparation for UI, and the negative side effects of UI medications may further decrease QOL.

Study Limitations

Using in-depth phenomenological interviewing resulted in the acquisition of incredibly rich and detailed data on the experience of the topic under investigation for the women involved. As a consequence of the comprehensive data, a smaller sample size was utilized, and seven women were interviewed. All of the women except one were Caucasian Canadian, and it is possible that the meaning of sexuality differs for women of varying cultural backgrounds. The women were diverse in terms of age, and injury duration and classification, but the participants were recruited in part by referral, and as a result, they may have shared similar views on the topic from previous conversations between friends prior to being involved with this research investigation. Also, the women who participated in this study may have tended toward a certain personality type as it would require a rather open individual to volunteer to discuss such personal information.

For one participant whose first language was not English (P7), clear understanding of all terms and what was being asked in each question may not have been achieved, though the researcher tried to the best of her ability to describe any term that was not understood by the participant, and to clarify any confusing language, though it is possible that some information may have been misinterpreted by either the participant, or the researcher. It was a concern of the researcher that participants would not be willing to discuss in detail information of such a personal nature, and though it was difficult for one participant (P6) to talk about sexuality, it is the researcher's impression that the other six other participants were very forth coming in the information that they provided. Given that this topic is novel and therefore very exploratory in nature, the sample in this study was quite heterogeneous in terms of age, injury, duration of injury, education, employment, and relationship and familial status. It may be beneficial for future investigations in this area to set more specific parameters for participants so that the information they derive is targeted toward more defined groups. Information from specific groups may then be compared to provide a representation of how this phenomenon may affect various subsets within an entire cohort.

Chapter 6- Conclusions

Trustworthiness

Qualitative trustworthiness was achieved by utilizing rigorous methods that were well documented throughout the data collection and analysis phases. This manuscript has gone through many levels of review, input and revision by the committee members.

Addressing the Research Questions

The experience of sexuality for women who are concerned about UI as a consequence of SCI has been outlined in the general descriptions and revelatory phrases from the women's transcripts. The experience has been described richly, candidly, and in a great deal of detail. These women were open and honest, and provided insight into their lived experiences of the phenomenon.

It was clear that UI had an immense impact on both sexual function and sexual satisfaction for women with SCI. In terms of its impact on sexual function, UI affected relationships, who they would be intimate with, when they would be intimate, the types of activities they would participate in and the way the sexual experience unfolded which now involved a great deal of preparation and planning. Urinary incontinence also impacted the sexual experience psychologically by creating negative emotions. The negative emotions included feeling unwanted and unworthy, a fear of rejection and embarrassment, and created worry and anxiety in the place of pleasure and enjoyment. In some cases, UI had robbed the women of their sexual lives completely as they were unwilling to subject themselves to those negative emotions, and they were not willing to deal with the way they would feel about themselves as adults who were unable to control

their own bladders during sexual activity, or the way they would feel about themselves as women due to the negative connotations that accompany UI.

Spinal cord injury in general had a definite impact on sexual satisfaction, and UI was one of the reasons for that. Urinary incontinence specifically impacted sexual satisfaction as the women were afraid to perform certain sexual activities, even though they felt good, because they feared that they may cause them to be incontinent. The women were also unable to enjoy the feeling of sexual activities because of a connection between pleasurable sexual sensations and UI. For the women who experienced this connection, there were times when they were unable to distinguish if they were voiding or having an orgasm because the sensation could feel the same. They became distracted by worrying about what it was that they were really feeling, and that took away from the enjoyment of the experience.

The main concerns the women had regarding sexuality had to do with the initiation of relationships and being able to maintain them, frustration with the way that sexual activities now occur and with the difficulty experienced in achieving orgasm, the questions and uncertainties they had regarding sexual function, and a fear of being hurt or injured during sexual activities. The main concerns regarding UI were the embarrassment and the work and inconvenience of the clean up, bladder infections, finding washrooms that were accessible, and the negative effects of UI medications.

In terms of sexuality as it related to UI, the major themes and concerns were that the women always found themselves comparing their sexual function and bladder function to the way they were before SCI. Even if progress was made, the women were disheartened knowing that things would never be the way they were before. The women

were bothered by the numerous issues they now had to worry about that were not a concern prior to SCI. They were concerned about the way a potential partner would react to UI in the event that it were to occur while being intimate, the way that their negative feelings toward UI affected their sexuality, the connection between pleasurable sexual sensations and UI, the fear of being incontinent while having a bladder infection and having to deal with infected urine, and having to disclose this information to new sexual partners which put them in a position where they may be rejected.

Other issues included those related to body image as a result of SCI that had huge negative effects on esteem and confidence, which in turn, had adverse effects on sexuality. A deficiency in the amount of information and resources that exists for women after SCI on the topics of sexuality and UI was a very large concern for the women in this study. They were frustrated with the lack resources that were available to them, and they stated that they would be willing to help improve this in any way possible so that there would be more information out there for other women who become injured. The women expressed their frustration and sometimes even apathy towards their Doctors because they said that they were uninformed about SCI and that they operated under false pretenses. As a result, some of the women go to their Doctor as little as possible and only when it is absolutely necessary. The women also discussed the numerous difficulties associated with having a child, and the challenges associated with raising a child after SCI. Though these women have the opinion that sexual function after SCI is more problematic for men than it is for women, they are unhappy that the majority of the information and resources caters to men. They are anxious and ready to have the spotlight on them, and for women's issues to take focus.

Future Directions

An emphasis needs to be put on the generation of information and resources regarding women's sexuality after SCI, and future studies should look further into the most effective methods for presenting this information, as well as the best time to offer it to the women. Rehabilitation facilities should provide a greater number of resources regarding sexuality, UI, and the effects of UI on sexuality. Having a specific person associated with rehabilitation facilities who specializes in sexuality and sexual function and who is knowledgeable about SCI available to discuss these topics could be an effective resource. It may be beneficial to create various and specified information packages on the topics of sexuality and UI that would be designed to target the women, their partners, and the Doctors who work with, or who may work with women who have SCI. This information may be more effective for the women and their partners if it is presented in an informal manner that is interesting and easily read. Having more resources to assist with the psychological and emotional aspect of UI and sexuality post-injury could improve esteem and confidence which could have a positive effect on women's sexuality.

Future studies should investigate whether the concerns of women who experience UI as a result of SCI are similar to the concerns of other groups of women who experience UI for alternate reasons, such as child birth or aging, or if these concerns are specific to this particular population.

By targeting the main concerns and issues of the women regarding sexuality and UI uncovered in this study, future research will be able to improve the QOL for women and their partner's after SCI.

Chapter Seven- References

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Chapter Eight- Data Manual

Data Manual

1. Research Ethics Board Letter of Approval
2. Recruitment Poster
3. Telephone Script
4. Letter of Invitation and Informed Consent Form
5. Interview Guide



Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Bioscience Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 8/26/2011
PRINCIPAL INVESTIGATOR: DITOR, David - Kinesiology
FILE: 11-024 - DITOR
TYPE: Masters Thesis/Project STUDENT: Jackie Cramp
SUPERVISOR: David Ditor
TITLE: Utilizing a Phenomenological Approach to Examine the experience of Sexuality for Women Concerned about urinary Incontinence following Spinal Cord Injury

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW Expiry Date: 8/31/2012

The Brock University Bioscience Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 8/26/2011 to 8/31/2012.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 8/31/2012. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Michelle McGinn, Vice-Chair
Bioscience Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.



Ethics Clearance File Number: xx-xxxx

[illegible]

Effects of Urinary Incontinence on Sexuality in Women with Spinal Cord Injury
Telephone Script:

Hello. My name is Jackie Cramp and I am a Masters student at Brock University. I would like to thank you for your interest in the sexuality study involving women who have spinal cord injury. Is now a good time to further discuss the details of the study?

If NO, NOT INTERESTED:

No problem, thank you for your time. If you change your mind, please do not hesitate to contact Dr. David Ditor at 905-688-5550 extension 5338.

If NOT NOW, ANOTHER TIME WOULD BE BETTER:

Absolutely, thank you very much. What would be the best time for me to contact you?

If YES:

This is a phenomenological study, which means that we are interested in discussing with you your own personal experiences regarding urinary incontinence and how it affects your sexuality. We would like to consider each individual's experiences, and also the meaning that has been personally attached to this phenomenon for each informant. This study will involve a one and a half to two hour interview during which time you will be asked questions concerning urinary incontinence and sexuality. The questions will be open-ended, and you will have the ability to answer them freely. Your interview will be kept confidential, and you will have the right to decline answering any questions that you may feel uncomfortable discussing, as well as the right to terminate the interview at any time.

The desired outcome of this study is to uncover prominent themes and patterns among the valuable information that will have been provided by each individual. This information can then be used as a guide for future studies to ensure that the main concerns and top priorities regarding this topic are addressed in future investigations.

This study has been approved in its entirety by the Brock University Ethics Committee. Considering all of this information, do you feel that you would be interested in participating in this study?

If NO, I AM NOT INTERESTED:

Ok, thank you for your time. If you change your mind, please contact Dr. David Ditor at 905-688-5550 extension 5338.

If YES, I WOULD LIKE TO BE A PARTICIPANT:

Great. Can we schedule an appointment for you to come into the lab at Brock University at which time you will sign a consent form and complete your interview?

If NO, THIS IS A BAD TIME TO SCHEDULE AN APPOINTMENT:

Not a problem. When would be a better time for me to call back to schedule you in? (Informant gives time to call back). Thank you ever so much. I look forward to being in contact with you soon to set up your interview. Have a great day.

If YES, I WOULD LIKE TO SET UP A TIME RIGHT NOW:

Perfect, what days/times work best for you? (Informant gives days/times that work for her. Time is set for interview). Thank you ever so much. I am looking forward to speaking with you at Brock University on (date of interview) at (time of interview). Have a great day.

Letter of Invitation and Consent Form

Utilizing a Phenomenological Approach to Determine the Effects of Urinary Incontinence on Sexuality in Women Following Spinal Cord Injury

Please consider this an invitation to voluntarily participate in a research investigation examining the effects of urinary incontinence on sexuality in women with spinal cord injury. This study will be directed by Dr. David Ditor of the Department of Physical Education and Kinesiology at Brock University. In this letter, you will find a detailed description of the study that will assist you in your decision to either participate, or not participate in this study. Please take a minute to carefully read through this letter. Do not hesitate to ask for clarification, or to ask any questions you may have regarding either this letter or the study. Should you require further information, please contact the principle student investigator or the faculty supervisor using the contact information provided below.

Principle Student Investigator: Jackie Cramp, Graduate Student, Department of Applied Health Sciences, Brock University.
(905) 242-4741
jc05vb@brocku.ca

Faculty Supervisor: Dr. David Ditor, Assistant Professor, Department of Physical Education and Kinesiology, Brock University.
(905) 688-5550, extension: 5338
dditor@brocku.ca

This study has been approved by the Brock University Ethics Board (File number xx-xxx). Should you require further information regarding the ethical approval of this study, please contact Lori Walker at the Brock University Ethics Board: 905-688-5550, ext. 4876.

PURPOSE OF THE STUDY

The purpose of this study is to examine the lived experiences of women who encounter urinary incontinence as a result of spinal cord injury, and to specifically discuss how it has affected them as sexual beings. The hope is that by exploring this often overlooked phenomenon we will be able to uncover the concerns with highest priorities for this population and direct future research towards to these identified areas.

STUDY PROCEDURES

Should you choose to participate in this study, you will be required to complete a one-and-a-half to two hour interview with the researcher. The interview will take place at Brock University, located at 500 Glenridge Avenue in St. Catharines, Ontario, in the Neuro-muscular Acquisition and Rehabilitation Laboratory (Welch Hall 143). The interview will be audio recorded and transcribed verbatim. Only one interview is required and will focus on your own experiences regarding the effects of urinary incontinence resulting from spinal cord injury on sexuality. The interview is an excellent opportunity for you to share your story, your knowledge, and your concerns.

POTENTIAL RISKS

Discussing experiences of a personal nature may create some feelings of trepidation, and talking about an issue of such importance may increase sensations of emotional stress. Please keep in mind that you will be able to avoid answering any questions that make you feel uncomfortable. Furthermore, the researcher has participated in a formal phenomenological interviewer training and is prepared to manage these risks.

POTENTIAL BENEFITS

Potential benefits of participating in this study include the opportunity to discuss your experiences, concerns, and frustrations regarding a significant topic that has, for the most part, been left unstudied. You will have the opportunity to see an interpretation of the meaning pertaining to your own experiences, and to consider your experiences in relation to those of other women. The information that is revealed during this investigation will have the ability to guide future research to ensure that the areas being targeted by researchers and health care practitioners represent the main concerns of the women they aim to help.

COMPENSATION

There will be no financial compensation for participation in this study.

CONFIDENTIALITY

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, with your permission, a pseudo name and anonymous quotations may be used. Shortly after the interview has been completed, you can request a copy of the transcript if you would like an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

VOLUNTARY PARTICIPATION

Participation in this study is strictly voluntary and the choice whether or not to participate is up to you. You have the right to forfeit answering any question(s) you choose while still remaining in the study, as well as the right to withdraw from the study at any time without penalty.

ACCESSING FINDINGS OF THIS STUDY/ PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. A one page summary of the findings will be mailed to you upon completion of the study. You will also have the option of receiving a full copy of the completed paper.

CONSENT FORM

I agree to participate in the study described above and I have made this decision voluntarily based on the information provided in the Information-Consent Letter. The study has been explained to me and any questions I that I had have all been answered to my contentment. I understand that I may ask additional questions in the future, and that I maintain the right to withdraw this consent at any time.

Name (please print): _____

Signature: _____ Date: _____

Person obtaining informed consent (please print): _____

Signature of person obtaining informed consent: _____ Date: _____

Interview Guide

Phenomenological Question- What is the experience of sexuality for women concerned about urinary incontinence following spinal cord injury?

Interview Questions (reformatted)

1. OPINION/VALUE

For the purpose of this study, we are primarily interested in sexuality, so I'm going to start by asking you to talk about your attitude towards sexuality and what it means for you to be a sexual person, and how has having a spinal cord injury changed or expanded that?

Probe Questions

1. What experiences contributed to how you formed these attitudes?
2. Tell me about your sexual activity before your injury.
3. Did you have any sexual difficulties prior to your injury? Can we talk about what was going on at that time?
(2 & 3= Sexual history assessment. Pre-existing sexual issues NOT resulting from SCI. Examples include: medical comorbidity, sexual abuse, rape, domestic violence, emotional issues, substance abuse, performance related issues, relationship factors...)
4. How do you feel about, or how have you been affected by the societal obsession with 'ideal' bodies? (Social pressures, Attractiveness, Non typical bodies)
5. Have you participated in sexual activities since your injury?
(“sexual activities” includes a broad range of things and does not necessarily refer to sexual intercourse)

2. DEMOGRAPHIC

In order to set a context for the rest of the questions, would you mind talking a little bit about yourself and your injury? (Background information)

Probe Questions

1. What is your age?
2. What was your age at the time of your injury?
3. How long have you been living with SCI?
4. What is the level/classification of your injury?
5. What is your ethnic background?
6. What is your highest level of education?
7. What is your current employment status?
8. What is your current relationship status?
9. What was your relationship status at the time of your injury? (to be continued...)
10. What is your sexual orientation?
11. Do you have any children? (to be continued...)
12. Are you taking any medications that you know have an effect on sexuality? On

urinary incontinence?

3. SENSORY

Since your injury, what body issues are you concerned about when participating in, or thinking about participating in sexual activities?

Probe Questions

1. Have you experienced UI since your injury?

IF YES:

- > 2. How long has it been since UI occurred?
- > 3. How frequently do you experience UI?
- 4. To what extent is UI a concern for you?
- 5. How does experiencing UI or a fear of experiencing UI affect your sexuality?
- 6. What precautions do you take prior to engaging in sexual activities to prepare for UI in the event that an incident should occur?
- 7. What connections do you think about, if any, regarding pleasurable sexual sensations and possible negative consequences as a result of those sensations? (prompt: UI and orgasm, fear to let go and enjoy, focused on possible UI, where did you learn about the connection between orgasm and UI?)

4. EXPERIENCE/BEHAVIOUR

Describe the absolute worst situation with urinary incontinence. It can be either the worst experience that has actually happened to you, or a description of your worst case scenario regarding urinary incontinence.

Probe Questions

- 1. What bothers you (do you think would bother you) the most about UI (if you were to experience UI)?
- 2. What is your biggest concern regarding UI?
- 3. In your experience, what factors do you find increase your likelihood of experiencing UI?
- 4. What factors have you been educated about that may increase your likelihood of experiencing UI?
- 5. How much disclosure do you feel is appropriate when discussing sex with a new potential partner?
- 6. What is the timing for this disclosure?
- 7. Describe all measures (if any) that you take to avoid UI.
- 8. How satisfied are you with your current urologic management program?

5. KNOWLEDGE

What resources are you aware of that are available to help educate you regarding women's sexuality and/or urinary incontinence after spinal cord injury?

Probe Questions

1. To what extent is information literature, pamphlets, support groups etc. that discuss sexuality and/or UI available for individuals after sustaining a SCI? Do you feel the amount of resources regarding these topics is adequate?
2. To what extent are these resources targeted towards women as opposed to men?
3. How much information has been provided to you regarding sexuality and/or UI since your injury? Do you feel the amount of information you received regarding these topics was adequate? Where did you get this information?
4. Think back, and tell me about your immediate response to the information you were provided with.
5. Who was the barer of this information? (ie: was it an able-bodied man? Would it be more helpful if this information came from a woman who had a SCI?)
4. When do you think is the ideal time after acquiring a SCI to receive information regarding UI? When would be the most helpful/beneficial time to receive information regarding sexuality?

6. OPINION/VALUE

How do you think the biggest adjustments regarding sexuality differ for men with spinal cord injury, versus women with spinal cord injury?

Probe Questions

1. How has having a SCI affected your self-esteem? Body esteem? Self confidence? Sexual confidence? Body image?
2. How have changes in mobility as a result of your injury affected you socially? Emotionally?
3. How have physical changes in appearance as a result of your injury affected you socially? Emotionally?

7. OPINION/VALUE

Tell me a story about a time or situation when your spinal cord injury affected you as a social being, either in a social situation, or in a social relationship.

Probe Questions

1. If separated/divorced since the injury: What do you think caused your relationship to end?
2. If single: Is being single a preference, or do you wish to be in a relationship? Why do you think you are single?
3. If in a relationship that started prior to the injury: In which ways has your relationship changed since your injury?
3. Prior to your injury, did you see yourself as a married person with children? And now?
4. What challenges do you face when establishing new relationships, both in friendship and romantic contexts, as a person with a SCI?
5. How does it make you feel when you have to talk to a new sexual partner about UI or the possibility of UI?

8. FEELING/EMOTION

In what types of situations or relationships have you experienced feelings of disappointment or frustration (regarding sexuality or UI) since your injury?

Probe Questions

1. Do you have any particular situations or relationships that come to mind? Tell me about an example.
2. Have you felt any disappointment or frustration in your sexual relationships since your injury? Explain.
3. What are the concerns of your significant other regarding your sexual relationship together? How are your partner's concerns similar or different from your own concerns?
4. How important do you feel open and honest communication regarding any sexual fears or concerns is in a relationship?
5. To what extent are your Doctors and/or health care providers comfortable discussing sexual function/ UI with you?
6. To what extent are your Doctors/health care providers knowledgeable on the topics of UI and sexuality in women with SCI?

9. FINAL QUESTION

What didn't I ask you that you wish I had? What else would you like to add/share/talk about that we haven't yet discussed? What questions do you have for me?